DOCUMENT RESUME

ED 305 772 EC 212 572

AUTHOR	Agosta, John M.; And Others
TITLE	Designing Programs to Support Family Care for Persons with Developmental Disabilities: Concepts to Practice.
INSTITUTION	Human Services Research Inst., Cambridge, MA.
SPONS AGENCY	Administration on Developmental Disabilities (DHHS), Washington, D.C.
PUB DATE	15 Sep 85
GRANT	90DD0049/01
NOTE	188p.; Portions contain small print.
AVAILABLE FROM	Human Services Research Institute, 2336 Massachusetts Ave., Cambridge, MA 02140 ($20.00).
PUB TYPE	Reports - Research/Technical (143) -- Viewpoints (120)
EDRS PRICE	MF01/PC08 Plus Postage.
DESCRIPTORS	*Delivery Systems; Demonstration Programs; *Developmental Disabilities; Family Involvement; *Family Programs; Family Role; Interviews; National Surveys; *Needs Assessment; *Program Design; Program Evaluation; *Public Policy; State Surveys; Theory Practice Relationship
IDENTIFIERS	Virginia

ABSTRACT

The report presents results of a 1-year project whose purposes were to explore issues surrounding service provision to families with developmentally disabled members, to assess the status of family support programs nationwide, and to apply this information to the task of developing a family support program in Virginia. Part 1 reflects findings of the overview phase of the study, discussing trends identified in the literature, results of a 50-state survey, and highlights of six state case studies. It also includes a detailed assessment of the major decisions that must be made in the design of family support policy. Part 2 includes information relevant to the formation of family support policy in Virginia. It begins with the findings of a survey of Virginia families who have developmentally disabled family members, continues with a summary of the deliberations of a conference on family support issues in the state, and ends with a series of specific recommendations for the implementation of discrete family support demonstrations. Appendices include a bibliography, interview guide used during site visits, descriptions of six state family support programs, and a Virginia survey questionnaire on family needs.(JW)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

Human Services Research Institute

ED305772

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

☑ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality

- Points of view or opinions stated in this document do not necessarily represent official OERI position or policy

DESIGNING PROGRAMS TO SUPPORT FAMILY CARE FOR PERSONS WITH DEVELOPMENTAL DISABILITIES: CONCEPTS TO PRACTICE

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
Valerie Bradley

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

EC 212572

DESIGNING PROGRAMS TO SUPPORT FAMILY CARE FOR PERSONS WITH DEVELOPMENTAL DISABILITIES: CONCEPTS TO PRACTICE

September 15, 1985

DESIGNING PROGRAMS TO SUPPORT FAMILY CARE FOR PERSONS WITH DEVELOPMENTAL DISABILITIES: CONCEPTS TO PRACTICE

PROJECT STAFF

HUMAN SERVICES RESEARCH INSTITUTE	THE COMMONWEALTH OF VIRGINIA
Valerie J. Bradley (Project Director)	Joseph Bevilacqua, Ph.D.
John Agosta, Ph.D.	Jack Noble, Ph.D.
Anne Rugg	Carol Singer-Metz
Rebecca Spence	Shirley Ricks
Susan Covert	Arthur Byrd

PROJECT STAFF ASSISTANTS

Samuel Austin, III
Karen Hartfield
Paul Nurczynski
Karen Williams

PROJECT OFFICER

Elsbeth Wyatt
Administration on Developmental Disabilities
Department of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

Human Services Research Institute
120 Milk Street, Eighth Floor
Boston, MA 02109

(617) 542-1812

This project was supported by the U.S. Department of Health and Human Services through the Administration on Developmental Disabilities (ADD Grant Number: 90DD0049/01).

The views expressed herein are soley those of the authors and should not be construed as representing the opinions or policy of any agency of the United States Goverment.

Additional copies of this publication may be obtained, postpaid at $12 per copy, check payable to Human Services Research Institute

The recommended citation for this publication is as follows:

Agosta, J., Bradley, V., Rugg, A., Spence, R. and Covert, S. (1985). Designing programs to support family care for persons with developmental disabilities: Concepts to practice. Boston, MA: Human Services Research Institute.

ACKNOWLEDGEMENTS

The authors recognize and appreciate the important contributions made by many individuals throughout the course of this project, including:

- those who provided us with information on family support programs around the country, and especially Debbie Jennings of the National Association of State Mental Retardation Program Directors who coordinated the national survey of existing state programs;
- members of the project's National Advisory Committee who reviewed project materials from time to time, including Robert Carl, Ph.D., Linda Cole, Harris Daniel, Dorothy Lipski, Ph.D., Lynn McDonald-Wikler, Ph.D., Jack Noble, Ph.D., Angela Novak, Ph.D., Kris Slentz, Ph.D., Edward Skarnulis, Ph.D., Warren Stambaugh, Lorna Stone, and Mark Tausig, Ph.D.;
- family support advocates in Virginia, including Linda Veldeer, Robert Stieg and Betty Burke, who offered us guidance and periodic assistance;
- persons in Virginia who helped direct the distribution of survey forms to caregiving families, including Edward Andrews, Mary Beth Bruder, Ph.D., Stacy Cacace, Irene Carney, Gerry Desrosiers, Marilyn Haga, Kay Harrison, Janet Hill, Robert Howman, Joanne Marchant and Mildred Taylor;
- conference participants who sharpened and broadened our understanding of key issues pertaining to family support and who shaped the final implementation plan;
- staff at the Administration on Developmental Disabilities, especially Elsbeth Wyatt, who reviewed drafts of our work; and
- staff at the Virginia Department of Mental Health who guided aspects of the project and participated in others, including Joseph Bevilacqua, Ph.D., Jack Noble, Ph.D., Carol Singer-Metz, Arthur Byrd, Shirley Traversy, and especially Shirley Ricks.

We are particularly grateful to the many families who took time from their busy day to respond to the statewide survey on family needs. By sharing their circumstances and personal experiences, these families did much to document the need for supporting families in Virginia and to guide the design of a responsive support program.

This report is dedicated to all those in Virginia who provide or have ever provided home care to persons with developmental disabilities.

TABLE OF CONTENTS

PAGE

Acknowledgements....................................iv
Table of Contents...................................v
Preface...vii

PART ONE: SUPPORTING FAMILY CARE: KEY CONCEPTS AND PRESENT PRACTICES

Introduction......................................1

The Needs of Families...........................2

-- Families and the Presence of a Member with Disabilities.........3

-- Needs of Persons with Developmental Disabilities...4

-- Overall Needs of Families.........................4

The Social Context: Forces For and Against Family Support Programs.........6

-- Factors Spurring Demand for Support Programs.......6

-- Obstacles to the Initiation of Support Programs....8

Present Status of the Move to Support Families.......12

-- Goals and Objectives..............................12

-- National Survey of Existing Programs..............13

-- Site Visits to Six States.........................23

Six Key Issues..................................32

-- The Role of the Family............................32

-- Program Eligibility...............................34

-- Means of Service Administration...................35

-- Permissible Services..............................38

-- Use of Existing Resources.........................39

-- Evaluating Family Support Programs...............41

PART TWO: SUPPORTING FAMILY CARE IN VIRGINIA

Introduction 46

The Needs of Families: Results of a Statewide Survey in Virginia..47

- -- Introduction..47
- -- Method..48
- -- Results..53
- -- Discussion..71

The Virginia Family Support Conference: Proceedings and Findings..74

- -- Approach Taken..74
- -- Technical Information and Experience Sharing..74
- -- Issue Resolution Sessions..83
- -- Concluding Remarks..90

A Plan for Supporting Families: The Virginia Family Assistance Pilot Program..91

- -- What is the Virginia Family Assistance Pilot Program?..91
- -- Why Provide Families with Assistance?..92
- -- A National and Statewide Perspective..93
- -- The Virginia Family Assistance Pilot Program......94
- -- Program Evaluation..97

APPENDICES

Appendix One: Composite Bibliography

Appendix Two: Interview Guide for Six State Site Visits

Appendix Three: Descriptions of Six State Programs

Appendix Four: Virginia Family Needs Survey

Appendix Five: List Conference Attendees

Appendix Six: Text of Keynote Address Delivered at the Family Support Conference

PREFACE

The following report, divided into two parts, presents the results of a one year project funded by the Administration on Developmental Disabilities of the United States Department of Health and Human Services. The purpose of the project was to explore the issues surrounding the provision of services to families with developmentally disabled members, to assess the status of family support programs around the country, and to apply the information secured to the task of developing a family support program in the Commonwealth of Virginia.

Part One of the document reflects the findings of the overview phase of the study and discusses trends identified in the literature, the results of a 50 state survey, and the highlights of six state case studies. It also includes a detailed assessment of the major decisions that must be made in the design of family support policy. Part Two includes information relavant to the formation of family support policy in Virginia. It begins with the findings of a survey of Virginia families who have members with developmental disabilities. It continues with a summary of the deliberations of a conference on family support issues in the state, and ends with a series of specific recommendations for the implementation of discrete family support demonstrations.

Findings emerging from this project reinforce the importance of discovering ways to assist families. Building an effective family support system, however, requires the cooperation of many, including parents, immediate and extended family members, neighbors, government officials at all levels, and professionals working both in the public and private sector.

At the core of any effective family support system must be a firm societal resolve to become active in encouraging rather than discouraging family care. This report presents evidence that such a commitment is emerging and that past biases in social policy and professional philosophy favoring out-of-home placement are coming under increasing scrutiny. Still in question are the respective roles that families, persons with disabilities, and government should play in directing the courses of family support servicves. History suggests that these roles seldom remain static but evolve continually with the social values of the times.

In addition, much still needs to be done to clarify the objectives of present family support initiatives, to estimate the number of families that could be affected, to resolve issues related to the administration and evaluation of statewide family support programs, and to involve all aspects of the community -- including the private sector -- in promoting family support. It is our hope that this report will provide needed information and stimulate the creation of expanded and improved family support programs, both in Viriginia and around the country.

PART ONE:

SUPPORTING FAMILY CARE: KEY CONCEPTS AND PRESENT PRACTICES

During the past twenty years, the norms and mores affecting American family life have undergone rapid changes. Parents of persons with developmental disabilities have endured these changes and have additionally experienced significant shifts in the way society responds to persons with disabilities. Until recently these parents were afforded only two residential service options -- they could forego traditional parental functions by placing their child out of the family home or they could provide care at home with little or no external support. A third option, however, is slowly evolving. In many states, families can provide care at home, and receive services to support their efforts and enhance their caregiving capacity.

To be sure, the growing interest in promoting quality home care is encouraging. Examination of present state and federal programs, however, reveals that no consensus has emerged regarding the best means for supporting families. The purpose of Part One of this report is to examine several factors that are central to designing any family support initiative, namely: 1) the needs of families, 2) the social context (factors for and against family-based care), 3) the present status of family support programs, and 4) six key issues affecting program implementation.

THE NEEDS OF FAMILIES

Bruininks (1979) observes that nearly everyone in society belongs to a family unit and that most persons live in such units, especially from birth to early adulthood. Present evidence suggests that these same observations hold true for persons with developmental disabilities. Most estimates of the number of persons with developmental disabilities who live in the community range around 2.5 million (Boggs and Henney, 1981). Further, it has been shown that only 243,669 persons with developmental disabilities live in out-of-home settings (e.g., institutions, psychiatric hospitals, nursing homes, foster homes, and community-based facilities) (Hauber, Bruininks, Hill, Lakin and White, 1982). Based on these considerations, it seems safe to assume that relatively few persons with developmental disabilities live away from their natural family during the developmental stages of their lives. Rather, the great majority (estimates run as high as 90%) stay at home because their families choose to provide family-based care (Perlman, 1983; Moroney, 1981; Bruininks, 1979).

Surprisingly, over the years little attention has been paid to the needs of these families. Recent efforts, however, have resulted in a growing literature on the topic. Though there is no comprehensive national data base that reflects the number and demographic characteristics of caregiving families, much has been learned about the effects of disability on a family and the needs of persons with disabilities. Such information can be used to gain an understanding of what support services families require to provide effective family-based care.

Families and the Presence of a Member with a Developmental Disability

The presence of a person with developmental disabilities in the home can present the family with a variety of extraordinary challenges. In general, available research suggests that the problems experienced by individual families are related to multiple factors including the seriousness of the family member's disability, the presence of maladaptive behavior, family characteristics, the family's emotional status, specific parenting patterns, the family's capacity for coping with adversity, and the availability of community support services (Crnic, Friedrich & Greenberg, 1983; Nihira, Meyers & Mink, 1981; Mink, Meyers & Nihira, 1984). As a result, Moroney (1983) notes that though not all of these families experience extraordinary problems, all are "at risk" because they are more likely to have difficulties than families without members with disabilities.

For many families the initial recognition that a severe disability exists in a child presents an immediate crisis that evolves into a life crisis. Several of the challenges families can face include:

- Natural reactions to the discovery that a family member has a developmental disability including a sense of shock or numbness, denial, grief, shame, guilt and depression (Fortier & Wanlass, 1984; English & Olson, 1978);
- Chronic stress (Wikler, 1981; Kozak & Marvin, 1984; Beckman-Bell, 1981);
- Social isolation resulting from perceived negative attitudes and/or rejection by kin or neighbors (Gottlieb, 1975; English & Olson, 1978);
- Financial costs or lost opportunities such as jobs, advancement, and education (Turnbull, Brotherson & Summers, 1985; Gliedman & Roth, 1980);

- Extraordinary time demands involved in providing personal care to the family member with disabilities (e.g., feeding, washing, dressing) (Dybwad, 1966; Apolloni & Triest, 1983);
- Difficulty with physical management (e.g., ambulation, lifting, carrying) and in handling socially disruptive or maladaptive behavior (Tausig, 1985; McAndrew, 1976); and
- Difficulty in undertaking normal family routines such as shopping or finding ample opportunity for recreation (Lonsdale, 1978; McAndrew, 1976).

Needs of Persons with Developmental Disabilities

Persons with developmental disabilities require special care due to physical and/or mental impairments that occur before age 22, and that result in severe functional limitations in a variety of life skills. Given this consideration, persons with developmental disabilities can have extraordinary needs pertaining to: 1) maintaining their health and well-being, 2) learning adaptive skills, 3) assuring their socio-behavioral adjustment, and 4) accommodating specialized needs stemming from their disability.

Overall Needs of Families

In addition to the several needs described above, two other factors must be considered. First, the needs of persons with developmental disabilities change over time as the individual progresses from one developmental plateau to the next (Konanc & Warren, 1984; Suelzle & Kennan, 1981). Second, as parents grow older their capacity to provide care changes. Moreover, in addition to meeting daily life requirements, parents must eventually give some thought to how the needs of their family member with disabilities can be appropriately met after they become infirm or die.

Table 1 displays numerous services that families and their members with disabilities could require. This list was distilled from a review of existing family support programs operating around the country and suggests that in addition to the direct care services required by the family member with disabilities the family also needs support services to enhance its caregiving capacity.

Table 1: List of Services Required by Persons with Developmental Disabilities and Their Families.

Home-Based Services Centered Around the Person with Disabilities	Services Centered Around Family Members
adaptive equipment	information and referral
educational/therapeutic services	temporary relief/respite
transportation	family counseling
medical or dental services	parent/sibling education
home barrier removal	homemakers
special clothing	chore services
special diets	housekeepers
diagnosis and assessment	cash assistance
medication	future financial planning
home health care	
attendant care	
recreational services	

These potential service needs are not ranked in order of importance. Each family has a unique cluster of needs and would place a different value on each service depending on their immediate circumstances. Additionally, many families may have needs that do not appear on the above list.

THE SOCIAL CONTEXT: FORCES FOR AND AGAINST FAMILY SUPPORT PROGRAMS

Factors Spurring Demand for Family Support Programs

The impetus for family-based care stems from two major ideological tides. The first is "normalization." This notion began in Scandanavia (Nirje, 1969) and was later expanded upon in North America. The philosophy of normalization presumes that persons with developmental disabilities should be served in programs and residences that are as normal as possible and that they be taught skills necessary for life in the community (Wolfensberger, 1972).

The second major movement, which is also premised on the integration of persons with disabilities into community life, is "mainstreaming." Supporters of this concept advocate that children with disabilities be educated in public school classrooms, and placed in non-segregated or "mainstream" classrooms to the extent possible. This notion led directly to litigation to secure free and appropriate education for children with disabilities and ultimately to the passage of the Education for All Handicapped Children Act in 1975 (Public Law 94-142).

The emergence of these moral imperatives coincided with a variety of other events that both helped to clarify these ideas and shape their implementation. Several of these events are listed below:

- A growing body of literature that shows that persons with developmental disabilities have the ability to grow and to learn -- this research was translated into the "developmental model";
- Mounting research on the debilitating effects of institutionalization and on the positive effects of home and community-based care (e.g., Close, 1977; Nihira, Meyers & Mink, 1983; Sokol-Kessler, Conroy, Feinstein, Lemanowicz & McGurrin, 1983; Schroeder & Henes, 1978; Conroy & Bradley, 1985);

- The ongoing improvement in instructional methodologies for persons with developmental disabilities of all ages to promote the acquisition, maintenance and generalization of skills (e.g., Engelmann and Carnine, 1982; Close, Irvin, Taylor and Agosta, 1981) and to remediate behavioral difficulties (e.g., Evans & Meyer, 1984; Hall & Hall, 1980);
- Increased evidence to show that parents can be taught specialized skills to meet the extraordinary needs of their developmentally disabled children (e.g., Snell & Beckman-Brindley, 1984);
- The use of broad scale litigation -- especially in the federal courts -- to bring about improvements in institutional care and ultimately to secure services in the community in the "least restrictive setting" (Bradley & Clarke, 1976; Bradley, 1978; Conroy & Bradley, 1985);
- The momentum of the civil rights movement which highlighted the plight of blacks in the country and which also illuminated the discrimination inherent in the treatment of other minorities including developmentally disabled citizens (Browning, Rhoades & Crosson, 1980);
- The growing consumer movement resulting in the creation of politically active parent groups (e.g., the Association for Retarded Citizens) and self-advocacy organizations (Browning, Thorin & Rhoades, 1984).
- Increasing evidence that home and community-based care is more cost effective than institutional care (Ashbaugh and Allard, 1983; Ashbaugh, 1984).

The effects of this movement on state-wide service systems are well documented. Recent information indicates that the total population of state institutions for mentally retarded persons declined from about 195,000 in 1967 to just over 125,000 in 1981 and the number of persons receiving community residential services increased from 26,000 in 1967 to an estimated 90,000 by 1982 (Lakin, Bruininks, Doth, Hill & Hauber, 1982). Likewise, comparison of Children's Bureau Survey results of 1961 and 1977 reveals that the absolute number of children with handicaps (emotional disturbance, mental retardation and physical handicaps) receiving public school services has more than doubled (MacEachron and Krauss, 1983). Finally, many states now offer parents of persons with a developmental disability a variety of supportive services including case management, parent education, financial assistance, respite care and family therapy. Clearly, the trend toward encouraging and supporting family-based care is gaining momentum, even in face of significant obstacles.

Obstacles to the Initiation of Family Support Programs

Three major barriers confront those charged with initiating family support programs: attitudinal barriers, political realities, and administrative uncertainties.

Attitudinal Barriers Three types of attitudinal barriers constrain the development of family support services. First, there is no consensus regarding the role of the family in the provision of care. Some professionals discount the family's capacity to make sound decisions about the welfare of their child or adult with disabilities. This presumption of incompetence in turn leads to recommendations for out-of-home placement as a matter of course.

Second, many families are themselves caught in a crossfire of conflicting interests and social role expectations. On the one hand, current lifestyles emphasize independence, self actualization and employment outside the home for women. Running counter to these values is a renewed interest in family-based care and a need for one family member to remain at home to provide care. Consideration of these contradictory perspectives can create for many families an unsettling sense of ambivalence regarding their future and the future of their offspring with disabilities.

Third, society has not reached a consensus regarding the public's role in private family affairs. This dilemma is both moral and political. Some believe, for instance, that parents themselves are responsible for any problems they encounter in bearing children and that the public should play a limited role in providing assistance. This position suggests that public sector dollars should not be used to pay for care provided by families to their family member with disabilities. In contrast, others believe that the presence of a person with a disability in a family should result in increased public involvement because of the special needs of family caregivers and persons with disabilities. Such involvement includes provision of support services to help the family live a life that is as close to normal as possible.

Political Realities Although far more persons with disabilities live at home with their families than in alternative residential arrangements, the great majority of service dollars are spent on out-of-home options. Consequently, providing families with comprehensive support services would require either additional resources and/or re-allocation of existing funds. Given a scarcity of fiscal resources and significant pressure to maintain current allocation patterns, many are reluctant to support further development of family support programs. In fact, some claim that it makes little sense to allocate additional resources for a service (i.e., family care) that is already being provided at no public cost. On the other hand, proponents of family care argue that all parties would benefit if the family were provided with needed services and point out that even a small decrease in family efforts would confront legislators and taxpayers with enormous financial burdens. From this perspective, it makes programmatic and fiscal sense to promote rather than ignore family efforts.

Administrative Uncertainities Establishing an effective state wide family support program is a complex political and programmatic task. As a result, state officials often approach the challenge with caution which in turn has meant that family support initiatives have developed very slowly around the country. Among the decisions that must be made are:

- What state department(s) or division(s) related to human services should administer the program?
- How many families have members with disabilities living at home and what are their characteristics and level of need?
- What families should be eligible (equity)?
- How should services be dispensed (cash subsidy, voucher, support services, or some combination)?
- What funding resources should be tapped (federal, state, county)?
- What role should the private sector (businesses) play?
- What services should be permissible?
- What limits (if any) should be placed on the amount of services provided per family?
- How much will the program cost today and in the near future?
- How should scarce fiscal resources be divided among various service modalities including family support programs, community based systems, and institutions?

These choices must also be made against a backdrop of changes in the traditional composition of families and roles of caretakers, including:

- increasing numbers of women entering the workforce;
- increasing numbers of single-parent families; and
- declining family size.

Together these trends suggest that the caretaking capacity of the family unit is being diminished. In response, parents may be more likely to seek out-of-home placement for their son or daughter with disabilities. Alternatively, they may respond by demanding greater public support for their efforts to maintain their child at home. In the years to come, we will be able to observe the impact of these factors on the way in which care is provided for persons with disabilities and their families.

PRESENT STATUS OF THE MOVE TO SUPPORT FAMILIES

Despite existing barriers, many states have attempted to address the needs of families by initating family support programs. The status of these efforts is discussed in this section of the report. First, the overall goals and objectives of family support programs are presented, followed by the results of a national survey of state programs, and information from an in depth analysis of six state family support programs.

Goals and Objectives

To design effective family support policy, viable goals must first be developed. Should services be justified solely on their ability to save tax dollars for the cost of out-of-home placement, or is the goal of improved quality of life for the family and the person with disabilities a sufficient public good? The weight of present evidence suggests that the enhancement of the quality of life of the family -- though not directly related to cost savings -- does result in substantial benefits to the larger society including increased family self-reliance, maximization of family cohesiveness, and improvements in the productivity of individual family members including the person with disabilities. Though these gains are somewhat more ineffable, they should likewise be part of any consideration of the merit or worth of family support policy.

In light of these priorities, there is little disagreement regarding the major goals that should guide any family support program: 1) to deter unnecessary out-of-home placement, 2) to return persons living in institutions back to a family setting, and 3) to enhance the caregiving capacity of families.

The National Survey

To acquire an improved understanding of the move to provide systematic support to families providing home care for persons with developmental disabilities, the Human Services Research Institute and the National Association of State Mental Retardation Program Directors undertook a national survey of existing statewide family support programs.

Method

Information was solicited from officials in the 50 states during a survey period beginning in November, 1983 and continuing through November, 1984. A family support program was defined as a statewide initiative, funded and monitored through the administrative auspices of the state, to provide systematic support to families with members with developmental disabilities.

The survey process included three steps. First, "survey contact forms" were sent to state directors of services for persons with developmental disabilities to determine the presence or absence of various family support services and to obtain the names of other knowledgeable persons in the state. Second, to gather information in greater detail, 57 "interview guides" were distributed to persons identified through the initial contact forms. These guides solicited specific information regarding program characteristics, funding levels, program effects, and factors influencing program growth. Finally, follow-up telephone inquiries to persons in several states were undertaken to help clarify information collected previously.

Response Rate and Limitations

Information was collected from all 50 states. Survey results, however, must be considered in light of limitations that became apparent during the course of the survey. The first is related to the absence of a well articulated and widely accepted definition of "family support." Such definitional ambiguity complicates the matter of surveying "family support programs" since survey respondents do not necessarily share a common frame of reference. What falls under the rubric of "family support" in one state may not be listed as such in other states.

Second, several states operate a variety of family support services which may be administerd by different state level divisions. Thus, directors of developmental disabilities programs may have neglected to mention relevant services administered by other state level agencies.

Third, the comprehensiveness of the responses secured varied considerably. Some state officials cooperated fully and forwarded much useful information. In contrast, others provided little information. As a result, survey results may underestimate the family support efforts in some states.

Results

All states but Oklahoma indicated the presence of some type of family support program. These programs were sorted into three administrative categories. First, Cash Assistance Programs provide money to families to offset the costs of habilitative materials or services. In such programs, families either receive a periodic subsidy or stipend to pay for future expenses or are reimbursed for costs of care incurred. Second, Supportive Programs provide families free inkind habilitative materials or services. In these programs states fund various agencies which in turn provide specified services. Finally, Combination Programs offer families both cash assistance and inkind support services.

Table 2: States Offering Family Support Services by Primary Administrative Category

---

Cash Assistance Programs

1. Connecticut
2. Idaho
3. Illinois*
4. Indiana
5. Louisiana
6. Minnesota
7. Nevada
8. North Dakota
9. South Carolina

Supportive Service Programs

1. Alabama
2. Alaska
3. Arizona
4. Arkansas
5. California
6. Colorado
7. Delaware
8. Georgia
9. Hawaii
10. Iowa*
11. Kansas
12. Kentucky
13. Maine
14. Massachusetts
15. Mississippi
16. Missouri
17. New Hampshire
18. New Jersey
19. New Mexico
20. New York
21. North Carolina
22. Ohio
23. Oregon
24. Pennsylvania
25. South Dakota
26. Tennessee
27. Texas
28. Utah
29. Vermont
30. Virginia
31. Washington
32. West Virginia
33. Wyoming

Combination Programs

1. Florida
2. Maryland
3. Michigan
4. Montana
5. Nebraska
6. Rhode Island
7. Wisconsin

---

* The Illinois state legislature has ratified a bill to permit operation of a cash assistance program but has not yet appropriated funding for the approved program. The state's Developmental Disabilities Council, however, has recently funded a $45,000 pilot support services program.

** The Iowa State Developmental Disabilities Council had funded a cash assistance program since 1981 but terminated funding on 9/30/84. The state does provide certain supportive services and is developing means for offering additional services through a private Community Living Foundation.

Table 2 displays the 49 states that report the existence of a family support program according to the administrative category that best exemplifies each state's support system. Review of this table shows that nine states operate cash programs primarily, 33 provide in-kind supportive services, and seven operate combination programs.

Though numerous states report the existence of a family support program, data presented in this section are confined to a sample of 22 states with the most "extensive" systems. Tables 3, 4 and 5 display information on these 22 states in six categories with each table displaying states in the same primary administrative category. These data show the variety in family support programs across the country, with respect to:

Date Initiated. Pennnsylvania was the first state to initiate a family support program of any kind (1972) and South Carolina was the first to initiate a cash assistance program (1974). Most programs (66%), however, were begun since 1980.

Eligiblity Criteria. All states impose eligibility criteria of some kind but these criteria vary by state and can be sorted into three informational categories. The first pertains to client characteristics. In all states a family must be providing care to a person with a developmental disability but states further restrict those who qualify based on such factors as disability type (eight states), age (six states), or severity of disability (five states).

A second category pertains to family resources. In seven states, service availability or cost to the consumer is made contingent on some type of means test, such as a sliding scale, or on some judgement of the family's capacity to cover the costs of care.

Table 3: Eight Cash Assistance Programs by Six Areas of Information

STATE	DATE INITIATED	TYPE OF PROGRAM	CLIENT/FAMILY EXPENSE LIMITS	NUMBER OF CLIENTS SERVED	APPROPRIATIONS (FY 1983-1984)	ELIGIBILITY CRITERIA		
						Client	Family	Placement
Connecticut	1981	Cash Program	$2,000 per year	15	$23,106	developmental disabilities	sliding scale based on income and family size; no other public assistance received	at risk of out-of-home placement or returning from such placement
Idaho	1981	Cash Program	$250.00 per month ($3,000 per year)	130	$47,000	developmental disabilities; under age 21		priority to those at risk out-of-home placement or returning from such placement
Indiana	1982	Cash Program	Determined by casemanager, maximum of $500 per month for respite	191	$185,000 (FY 1985)	developmental disabilities		priority to those at risk of out-of-home placement
Louisiana	1983	Cash Program	$375.00 per month ($4,500 per year)	25	$112,500	mental retardation		
Minnesota	1975	Cash Program	$250.00 per month (3,000 per year)	190	$525,000	primary diagnosis of mental retardation; under age 18; priority to severest disability	priority to greatest resource needs	
Nevada	1981	Cash Program	$286.00 per month ($3,432 per year)	67	$110,000	profound mental retardation	insufficient income to cover costs of care; sliding scale based on family income & size	
North Dakota	1981	Cash Program	$15/week for basic care; $35/week for services/ treatment ($2,600 per year)	200	$200,000 (3 year pilot)	developmental disabilities; under age 21		
South Carolina	1976	Cash Program	150.00 per month. ($1,800 per year)	15	$23,000	mental retardation	insufficient income to cover costs of care	

Table 4: Seven Support Services Programs by Six Areas of Information

STATE	DATE INITIATED	TYPE OF PROGRAM	CLIENT/FAMILY EXPENSE LIMITS	NUMBER OF CLIENTS SERVED	APPROPRIATIONS (FY 1983-1984)	ELIGIBILITY CRITERIA		
						Client	Family	Placement
California	1982	Support Services	varies by individual but no set limit	35,000 (all ages)	$5,100,000 (for persons under 18 years)	developmental disabilities		
New Jersey	1980	Support Services	No limit on intervention services but only 30 days respite/year	850	$967,187	mental retardation	means income eligibility standard	
Ohio	1983	Support Services	$2,500 per year	Program initiated 4-1-84	$700,000	developmental disabilities		
Oregon	1983	Support Services	No set limit	about 1,000	$3,100,000	developmental disabilities; under age 6		
Pennsylvania	1972	Support Services	No set limit	11,548	$3,487,278	mental retardation		
Vermont	1978	Support Services	$990.00 per year	260	$301,279	mental retardation		
Washington	1977	Support Services	$750.00 per year	800	$2,154,000	developmental disabilities		

Table 5: Seven Combination Programs by Six Areas of Information

STATE	DATE INITIATED	TYPE OF PROGRAM	CLIENT/FAMILY EXPENSE LIMITS	NUMBER OF CLIENTS SERVED	APPROPRIATIONS (FY 1983-1984)	ELIGIBILITY CRITERIA		
						Client	Family	Placement
Florida	1978	Combination Program	Based on need; no maximum	8,227 (210 in Cash Program)	$21,000,000 ($1,200,000 for Cash Program)	developmental disabilities		at risk of out-of-home placement if services not received
Maryland	1984	Combination Program	No set limit; based on need within reason	303	$197,000	developmental disabilities under age 22		at risk of an out-of-home placement
Michigan	1984	Cash Program	$225.00 per month ($2,700 per year)	Estimated at 2,000	$5,700,000 (est. FY 1985)	severe mental or multiple impairment, autism; under age 18	family taxable income for year preceding application cannot exceed $60,000	
	1983	Support Services	No set limit; limited by budget	355	$495,000	developmental disabilities		
Montana	1975	Combination Program	$1,385 per year	600	$1,025,000	No set priority but preference to young and severe disabilities		
Nebraska	1982	Combination Program	$300.00 per month averaged over one year	115	$200,000	developmental disabilities	insufficient income to cover costs of care	
Rhode Island	1981	Combination Program	$60/week for basic care, $15/week for training ($3,900/year)	65	$256,000	mental retardation; mental illness; chronic impairments		resident of state residential facility for 90 days to receive a cash subsidy
Wisconsin	1984	Combination but varies across the state	$3,000 per year	197	$125,000	severe disabilities; children	no access to sufficient funds to cover costs of care	at risk of an out-of-home placement or returning home from such placement

The third category involves consideration of the placement status of the person with disabilities. Six states prefer that the person be at risk of an out-of-home placement, while three states require that the person must be returning home from such placement. Rhode Island stipulates that to receive a cash subsidy, the family member with disabilities must have been a resident of a state residential facility for 90 days.

Client/Family Expense Limits. Most states (16) set some specific limit on the amount of money that can be expended annually on individual families. Though six states indicate that no such limits exist, officials in these states readily admit that the total program budget naturally restricts the amount that can be spent and that costs must be held "within reason."

Numbers of Clients/Families Served. For the most part, states with the greatest population densities tend to serve more families than states of lesser population density. California serves the most families by far (35,000) while Pennsylvania administers the second largest program (13,000). Connecticut and South Carloina operate the smallest programs (15 families). The total number of persons served by the programs profiled is 61,963 (exclusive of those served in Ohio because such figures were unavailable at the time of the survey). This figure is considered by many to be far short of the potential demand given: 1) the overwhelming majority of persons with developmental disabilities live at home with their natural families (Perlman, 1983; Maroney, 1981; Bruininks, 1979), and 2) 243,669 persons with developmental disabilities are served in out-of-home residential alternatives, including institutions and community-based arrangements (Hauber et al., 1982).

Appropriation Levels. As expected, the amount of funds appropriated varies with the number of clients/families served. Appropriation levels ranged from $21,000,000 for a combination program in Florida serving 8,229 families to $23,000 for cash assistance programs serving 15 families in both Connecticut and South Carolina. Moreover, survey findings show that cash programs are generally funded at lower levels than either support or combination programs with combination programs generally receiving the most fiscal support.

Table 6 lists all 22 states and illustrates what services are permissible besides case management. In addition to these services, at least 11 states have provisions for families to acquire services that are not regularly permitted. For example, families in Pennsylvania can present extaordinary service needs to local review boards. Though state guidelines influence decisions, these boards are at some liberty to ratify the provision of unique services. Likewise, Michigan will allow any service the family views as contributing to its capacity to provide care.

Review of Table 6, however, suggests significant variance among states regarding the range of services offered. The services noted most frequently are temporary relief or respite care (21 states) and adaptive equipment (20 states). The least noted services are information and referral and room and board for family members (two states). Maryland and Nebraska offer the most comprehensive array of services (14 services), while Indiana offers the fewest (three services).

Table 6: Permissible Services in 22 Family Support Programs

SERVICES	STATES																						TOTAL
	CA	CT	FL	ID	IN	LA	MD	MI	MN	MT	NE	NV	NJ	ND	OH	OR	PA	RI	SC	VT	WA	WI	
Adaptive Equipment	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X			X	X	X	X	X	20
Educational or Therapeutic Services for disabled person (examples include physical, speech or vocational therapy, behavior management)	X	X	X	X		X	X	X	X	X			X	X		X	X	X	X	X	X		17
Transportation	X	X	X	X	X		X	X	X	X	X	X		X		X			X		X	X	16
Medical or Dental Services	X	X	X	X	X	X	X	X	X		X			X				X	X			X	14
Housing Modifications	X		X	X		X	X	X	X		X			X	X		X	X	X			X	14
Special Clothing	X	X	X	X				X	X			X		X						X		X	10
Diet or Nutrition Services			X	X		X	X	X	X			X		X	X							X	10
Diagnosis and Assessment	X		X	X				X	X	X	X			X								X	9
Medications		X	X			X	X	X	X		X								X				8
Home Health Care				X		X	X	X			X		X	X									7
Personal or Attendant Care	X					X	X	X			X												5
Recreational Services			X	X										X			X					X	5
Information and Referral										X						X							2
Temporary Respite or Relief	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X		X	X	X	X	X	X	21
Family Training or Counseling	X	X	X	X		X	X		X	X	X			X	X	X	X	X				X	15
Homemaker	X						X		X		X		X				X	X					7
Chore Services	X						X				X												3
Housekeeping	X						X				X												3
Room/Board for Family (for traveling related to provision of care)			X								X												2
TOTAL:	13	8	13	12	4	10	14	12	12	7	14	5	5	12	5	4	6	7	7	4	4	10	
Provisions for permitting unique services not available elsewhere	X	X	X	X	X		X	X		X							X		X			X	11

The Six State Site Visits

While the 50 state survey provided valuable information on family support services around the country, a more in-depth assessment was required to understand how and why particular models took root in particular state contexts. Project staff, therefore, reviewed the results of the 50 state survey and selected six states for site visits and intensive analysis. The selection process was designed to ensure geographic representation, a mix of program types (support services versus cash subsidy), a variation in the level of resources expended, a range of eligibility criteria, and a spectrum regarding dates of inception. Using this process, the states selected were Washington, Michigan, Ohio, Rhode Island, Pennsylvania, and Florida. Detailed descriptions of the family support programs in these states are found in Appendix 3. What follows is an overview of the methods used to secure information and the findings of the site visits.

Prior to the conduct of the site visits, project staff prepared an inquiry guide covering a variety of issues including the program's history, characteristics, and strengths and weaknesses. The interview guide is included in Appendix 2. Visits were scheduled for two days each and included interviews with a range of key informants. Interviews were scheduled well in advance in order to ensure contact with family members, legislators, state administrators, advocates, and service providers.

Duration of Family Support Services

The programs visited had been in operation for varying lengths of time. The oldest program was Pennsylvania's Family Resource Services initiated in 1972. The newest services -- Michigan's cash subsidy, Washington's community options and community alternatives programs, and Ohio's family resources -- were developed and implemented in 1983 and 1984. Programs in Rhode Island and Florida grew up during the mid to late seventies.

Administering Agency

Without exception, the family support programs in the six states visited are administered by state mental retardation and/or developmental disabilities agencies. In no instance did the target group extend beyond the mandated clientel of the agency. Direct administration of the programs was by and large carried out by the designated local agency responsible for providing or contracting for other mental retardation/developmental disabilities services (e.g., county boards or regional offices). Support services (e.g., respite care, attendant care, special therapies, etc.) are provided primarily by private agencies under contract with the state or by individuals who are responsible directly to the parent.

Program Histories

The theme that is common to all of the programs is the central and crucial role of played by families themselves in the initiation of family support initiatives. Almost without exception, it was organized family groups that pressed the case in state legislatures for the passage of family support legislation. In some instances, for example in Michigan, the parents groups were ad hoc and not directly linked to the existing statewide groups like the association for retarded citizens. In other states, like Florida, the association for retarded citizens was the pivotal organization. Another key factor in the success of family support initiatives appeared to be the presence of a sympathetic legislator who was sensitive to the issues facing families and who could shepherd the bill through the legislative process.

Another fact that emerges from the analysis of the six state programs pertains to the role of the family in directly service delivery. Programs that were designed most recently, Michigan and Ohio, encourage greater involvement of family members than those established in the 70s. The Michigan family subsidy program leaves the decisions regarding how funds will be spent on behalf of family members with disabilities totally up to the family. In Ohio, family resources services have been designed to include families in program design and planning at all levels. Conversely, the program in Pennsylvania, which was the first in the nation, is implemented through county mental health and mental retardation programs with relatively little input from families. Likewise, the Home Aid program in Washington is basically managed and administered through regional state offices with only perfunctory participation by families.

Finally, the history of these programs shows that though they have continued to grow slowly over the years, they still run a distant second to state spending on out-of-home services for individuals with developmental disablilities. Also, with the exception of the Michigan program, those interviewed in the remaining states noted that family support programs do not approach the extent of potential demand.

Program Purposes

Virtually all of the programs reviewed had as a purpose -- either explicitly or implicitly -- the prevention of institutionalization. In some cases, such as the program in Rhode Island and the Program

Options project in Washington, the program purpose also extends to the movement of persons with disabilities out of institutions. Additionally, most of the programs are aimed at improving the capacity of families to care for members with disabilities and ensuring that individuals are served in the least restrictive circumstances.

Thus, though some programs are premised on the goals of improving the family's quality of life and enhancing the life chances of persons with disabilities, in the background there is still the tacit aim of saving public funds by diminishing the demand for residential services.

Program Type

The family support programs in the six states ranged from support services alone (Ohio and Pennsylvania), to a combination of support services and cash subsidies (Washington, Michigan, Florida, and Rhode Island).

Eligibility Criteria

Pennsylvania, Ohio, and Michigan limit family support services to families in which the individual with disabilities has mental retardation. The Rhode Island cash subsidy program is likewise limited to persons with mental retardation, but the state's early intervention program is open to other individuals with developmental disablilities. All of family support programs in Washington and Florida are available to families with whose members are mentally retarded as well as physically disabled.

The majority of states visited had no age limit for cash and/or services. The Michigan cash subsidy program, however, was limited to families with children with disabilities under 18 years old, and the

Rhode Island early intervention program is limited to families with children under 3 years of age.

Rhode Island specifically limits its cash subsidy program to individuals who meet the criteria for institutional admission. In Florida potential clients must be at risk of institutionalization and in the Washington Program Options and Community Alternatives projects, clients must be in an instituion or eligible for an ICF/MR level of care.

The only state that specifically provides services to foster families is Pennsylvania.

Expense and Service Limits

Among states that offer some form of cash assistance, Florida has no ostensible limit on the amount of money that can be spent on any one family, Michigan allows each eligible family $2700 per year, and Rhode Island allows a minimum of $1560 and a maximum of $4530 per family. In Washington, the state will reimburse a family 80% of the cost of institutional and/or ICF/MR care. With respect to support services, Washington limits the number of respite days in its Home Aid program to 27 per year, Pennsylvania limits family service to four 24 hour sessions per family per month (or 48 days), and in Ohio there is a limit of $2500 worth of service per year.

With the exception of the Michigan cash subsidy program, however, -- which is more like an entitlement than the other state programs -- the majority of state family support services are ultimately constrained by the amounts appropriated by the state legislatures.

Numbers Served

Numbers served in the six states include the following:

Washington: 2100-2200 in the Home Aid Program, approximately 9 families in Program Options, and 80 - 90 in the Community Alternatives Program.

Rhode Island: 65 in the Cash Subsidy Program, and 390 in the Early Intervention Program.

Florida: 8,229 in the Independent Family Living Program, and 210 in the Family Placement Program.

Ohio: No figures were available at the time of the site visit.

Pennsylvania: 13,000 people in the Family Resource Service program.

Michigan: 2,000 to 2,300 in the Cash Subsidy Program, and an unknown number receiving support services.

Permissible Services

In Michigan, families can use their subsidy in any way that they wish. In Florida, cash grants are only made on a reimbursement basis after an approved purchase has been made. Washington's Community Alternatives Program, which is part of the state's community services waiver, will finance case management, habilitation, respite, nursing, equipment and supplies, physical therapyt, occupational therapy, speech therapy audiology, behavior therapy, dental and medical care. Rhode Island's cash subsidy program has a similar list of eligible services.
The support service programs in Florida, Ohio, Pennsylvania, and Washington offer a similar range of services although they vary in availability depending on locality and the amount budgeted in any given year.

In addition to a list of eligible services, Pennsylvania, Florida, and Michigan also can convene special review boards to approve other services where individual circumstances warrant.

Amount and Source of Appropriation

The family subsidy program in Michigan is supported entirely by state funds and the appropriation for the first full fiscal year of operation (84-85) was $4.5 million. Support services in that state are also funded out of state revenues at a cost of $4 million. Ohio's new Family Resources Services program was funded for fiscal year 1985 at $2 million in state general funds. Pennsylvania's program is funded 90% state 10% county for a total of $3.6 million in fiscal year 1984. Florida's expenditures for its two initiatives are a mixture of state funds (about 52%), federal Title XIX waiver funds (21%), and other sources (about 26%). The Independent Family Living program was funded at a total of $21.4 million in Fiscal Year 1985, of which $1.2 million was allotted to the Family Placement Program. The Washington Home Aid program was funded at approximately $2.5 million in state funds for the 1982-1984 biennium, and figures for the Community Alternatives Program were not available. Since the Community Options Program is premised on a direct cost saving over institutional care, no appropriation was made. Finally, in Rhode Island, the state's family support initiatives are funded by a mix of state funds (about 60%), federal funds (about 35%), and other private sources (about 5%). Total expenditures totaled $256,000 for the cash subsidy program in Fiscal Year 1983 and $670,000 for the early intervention program in Fiscal Year 1984.

These figures are very interesting since they suggest an extremely wide range appropriations per client served. For instance, though Pennsylvania serves 13,000 families per year, the total appropriation of $3.6 million amounts to only about $277 per family per year. Conversely in Florida, the expenditure is over $2500 per year. Likewise in Michigan, eligible families are receiving $2700.

Further, only Florida and Rhode Island are making significant use of Title XIX funding. Washington, through its Community Alternatives Program, is using Medicaid funding for 80 to 90 families.

Strengths of Family Support Programs

Cash subsidies rated high among family members interviewed because of their individualized character. Instead of a preset menu of services, subsidies make it possible for family members to determine their own particular service needs. A further strength of cash subsidies such as the one administered in Michigan has to do with the ease of implementation and the low administrative overhead that results.

With respect to service organization, those programs that included family members at all stages of service planning and provision, at the individual as well as the system level, were seen as being more responsive to the needs of families. Further, there was a strong consensus that the presence of recpite and other forms of parental assistance were crucial to the well-being of families coping with the care of seriously disabled family members. Those programs that offered a wide range of possible support services and a schedule of service delivery geared to the convenience of the family and not the provider were also seen as being the most valuable.

Finally, family support programs were seen as heading off out-of-home placement or certainly delaying the move of a person with disabilities person out of the home. Research in Michigan documented the impact of family support on such decisions.

Weaknesses of Family Support

The major weakness noted in some of the states had to do with the overly bureaucratic character of some of the programs. Specifically, clients of the Home Aid program interviewed in Washington felt that respite schedules were inflexible and required family members to plan "crises" well in advance of the event. There were also concerns voiced by parents in Pennsylvania regarding the lack of responsiveness among county administrators of family support programs and participation of families in service planning.

Another recurring weakness noted in some of the states had to do with the shortfall between what was available for families and the potential demand for services. This sentiment was particularly strong in Washington and Rhode Island.

Finally, there was concern voiced in many of the states regarding what appeared to be arbitrary exdclusions of groups of persons with disabilities and their families who could benefit from family support services including persons with disabilities of normal intelligence and persons with severe mental illness.

SIX KEY ISSUES

Based on the findings from the National Survey and the six state profiles just described, six key issues surrounding the development of family support programs emerge: 1) the role of the family, 2) program eligibility, 3) service administration, 4) permissible services, 5) use of existing resources and facilities, and 6) evaluation of programs.

The Role of the Family

Though the great majority of persons with developmental disabilities have always remained at home, recent policy in the human services field often discounted the family's role in providing care (Skarnulis, 1976; Demos, 1983). The incompetence of the family to provide care was frequently presumed while professionally supervised residential arrangements were funded instead. Survey results suggest that recent calls to "support not supplant" the family have not gone unheeded as numerous states have initiated family support programs.

An underlying theme of family support pertains to the role that consumers can play in the provision of care. A primary finding of this project is that family support programs should be designed in ways that:

- recognize the family's underlying commitment to care for their family member with a disability;
- embrace practices that promote, not discourage, increased family independence from the formal service system;
- take seriously the view of the family and the person with disabilities with regard to how services should be designed and rendered; and
- treat the person with developmental disabilities not as a passive recipient of services but as someone who has individual rights and who should participate in his or her own care to the extent feasible in order to develop as an informed self-advocate.

When these principles are used to guide program design, the family support system, while based on the aggregated need of all service consumers, is ultimately accountable to individual consumers. As such, it empowers families and persons with disabilities on two levels:

- Systems level: Service consumers have significant input into the substance, administration and planning of services; and
- Family level: Service consumers have some control over the services they receive. This suggests that flexible multiple service options should be available and that families and/or persons with disabilities be able to select services from a comprehensive service menu.

Some professionals warn that many family members and persons with disabilities are incapable of accepting an empowered role or want to be more dependent on outside direction. However, the absence of needed skills among some or the reluctance of others does not justify the substitution of professional judgement in all cases. To do so fosters dependence on professionals and discounts the potential of the family and persons with disabilities to make competent service related decisions.

Instead, service models must be founded on the assumption that all families and persons with developmental disabilities are potentially capable and willing to make responsible decisions. Given this presumption, the challenge for service planners is to establish partnerships among families, persons with developmental disabilities, and professionals that will empower service consumers to the maximum feasible extent.

Of course, there are limits to the emotional, physical and financial resources of parents and to their expertise. When first confronted with the advent of disability, many family members have little understanding of what overall needs they will have. Moreover, even as time passes, some families will be unable or unwilling to accept an empowered role. Similarly, many persons with developmental disabilities will be unable to make responsible decisions on their own behalf. The eventual goal of the system, however, must be to equip service consumers, be they family members or persons with developmental disabilities, to provide and/or obtain competent care, rather than to ensnare them in bureaucratic mazes and make them dependent on professional judgements.

Program Eligibility

States cannot afford to provide comprehensive services to all families who have members with developmental disabilities. Consequently, service planners must devise equitable criteria for restricting the number and/or type of persons served. In structuring such criteria, several hard choices must be made. For instance, all states require that a family member have a "developmental disability." However, should the functional definition of developmental disabilities in the federal law be applied or should eligibility be restricted to conditions such as mental retardation, autism, or multiple impairments? Many states have chosen to restrict the definition, while others have adopted more liberal criteria. Certainly this aspect of eligibility raises the spectre of competition among various disability groups. Likewise, states must decide whether families confronting similar problems should be treated similarly or whether families should be served based level of income (Brown, Johnson, & Vernier, 1983).

Who should receive services is a preplexing issue, one that severely tests a society's capacity to distribute scarce resources equitably to those in need. The existing variance among state eligibility criteria reflects each state's own solution to the problem. Such variance, however, has resulted in an inequitable national response to providing family support since families are treated differently from state to state.

Means of Service Administration

The issue of service administration includes both how services are to be administered (i.e., in what format?), and by whom (i.e., what agency(s) will be involved and in what capacity?). Services can be made available to families through at least three administrative formats: cash assistance, supportive services or some combination. Each of these formats, however, has certain strengths and weaknesses.

Cash assistance programs

As noted earlier, this approach is favored by many because it shifts the locus of control away from the state and toward parents. With time, the aggregate purchasing preferences of families should dictate the types of services that are available and service providers should be held accountable directly to parents.

But this approach also raises concerns. First, should parents be provided with cash prior to purchasing services or should they be reimbursed after they incur the expense? It would seem that receiving cash prior to purchasing services would relieve the strain on family resources. In contrast, the state might prefer a reimbursement strategy because it would be easier to direct and track what is purchased.

Second, should cash received by parents be considered taxable income? If viewed as income, the state could be placed in the undesirable position of subsidizing federal tax revenues. Further, such income could jeopardize a family's eligibility for other public assistance benefits such as Supplemental Security Income (SSI). In contrast, if cash assistance is viewed as a "benefit," as it is in Michigan, the cash received by parents would not be taxable and would not affect eligibility for public assistance.

Finally, cash assistance programs presume that parents have sufficient knowledge regarding the needs of their child or adult with disabilities and the quality of available services. To the extent they do, they will spend their cash efficiently. But some parents may be unprepared to choose and purchase services wisely. Thus, many believe that cash assistance programs must be complemented with case consultant services and parent education to provide parents with the knowledge they need to choose appropriate services.

Supportive services

Most states with family support programs elect to provide supportive services exclusively. The advantage of this approach is that the locus of control rests with the state and various service providers. As a result, a cohesive service structure can develop throughout the state that can be directed and monitored centrally.

Ironically, this asset is considered by some analysts to be a liability. Though families help decide which services they receive in this scheme, the types of services and service providers are pre-determined by the state. Consequently, families take a secondary role in deciding which services are needed and which services should be funded. Additionally, because the state contracts with service providers, providers are accountable primarily to the state and secondarily to parents.

Combination programs

These programs offer an opportunity to develop a system that maximizes the relative strengths of cash assistance and supportive administrative styles, while minimizing their weaknesses. There are at least two unique advantages to this approach. The first pertains to funding. Review of existing cash assistance programs shows that the funding source is often state revenue. By adopting a combination approach, however, available resources can be expanded by acquiring federal Title XIX dollars (through the Community-based Waiver Program) to fund certain supportive services like parent education or respite services. Rhode Island is one state that has pursued this course.

Second, if the primary service goal is to promote family independence from the state, combination programs can be very effective. Initially, families may primarily need supportive services (e.g., parent training to learn specialized skills). Later, after their skills and confidence grow, families can take increasing responsibility for directing their own services by giving up inkind supportive services in favor of cash assistance.

Deciding how to deliver family support services, and through what agency(s) they should be administered, is a complex issue that is influenced by each state's historical response to people with developmental disabilities and to the political and economic environment. There are factors, however, that are present in every state that are likely to shape the direction of delivery of family support services. For instance, such services are closely linked to the communities in which the needs arise, and it would appear that local governments will have to play an important role in managing and/or delivering family support services. Moreover, the continuing pressure to contain government spending on social programs seems likely to create more pressure to increase the role of the private sector vis-a-vis the public sector in the area of family support services. Those cost pressures as well as the generic character of many family support services will also encourage greater integration of service delivery and less separate and parallel services specific to people with developmental disabilities.

The demand for cash subsidies, vouchers and other mechanisms that tend to empower families seems to be emerging as a companion to the demand for these services in general. None of these observations should be especially surprising. However, taken together, they indicate that family support services represent an increasingly significant departure from the way in which services are provided to people with developmental disabilities and their families, and they may ultimately have a reciprocating effect on the entire system of services for persons with disabilities.

Permissible Services

The type of services available varies by state. Some states offer few services while others provide an extensive array. Additionally, state agencies tend to fund service categories (e.g., respite, transportation, parent education). No two families, however, have identical needs. Moreover, existing needs are not static but evolve with time. A preferable program design would include multiple service options that could be tailored to individual families. In this way, instead of being restricted to certain services, families could choose from a menu of permissible services. While some families could benefit from professional advice before choosing services, the primary intent of this type of program is to develop services that revolve around and exist for families.

Use of Existing Resources

It must be understood that developing family support systems does not necessarily imply a need for funding an entirely new and separate service system. Much can be done to build on existing resources. For instance, greater use can be made of public school facilities, community college campuses, community centers, church facilities, and other existing sites to serve as day care centers, recreational sites, evening respite centers, or training sites for persons with developmental disabilities and their family members.

Similarly, initiatives must be undertaken to encourage improved coordination between existing service providers such as public school teachers, family support providers, case consultants, medical care staff, vocational instructors, and specialized therapists (e.g., speech and physical therapists). None of these providers should work in a vacuum since the family must interact with each. Thus, care must be taken to coordinate the level, type, and content of services to maximize their combined effect. This issue takes on extraordinary importance during "transition periods" in the lives of the person with disabilities and his/her family (e.g., when the person with disabilities "ages out" of the public school system, when parents grow too old to provide home care, when the person with disabilities desires to move away from his or her family).

Greater emphasis should also be placed on using computer technology to assist parents. On a local level, computer systems maintained by organizations in either the public or private sector could be used to encourage greater cooperation among families. For instance, listings of persons that could assist parents could be maintained and shared with parents as needed. Such persons could include qualified respite providers, building contractors experienced with removing home barriers, dentists or doctors who understand the special needs that a person with disabilities may have, and other professionals whose services families may require. In addition, such networks could be used to manage information on special equipment or toys that parents may wish to share or exchange with one another.

On a state or national level, existing information systems could be used to foster more effective means of providing families with information pertaining to the state-of-the-art in instructional practices, useful state and federal tax relief programs, and novel private sector initiatives. This type of information would help make parents aware of what is available on a broader systems level and would promote greater cooperation among caregiving families.

Likewise, service planners and administrators could make greater use of computer based information systems. Computer technology can be used to guide development of resource allocation plans pertaining to family support, to track expenditures for such services, and to monitor the processes and outcomes of service provision.

Obviously, any plan to utilize existing resources will require a firm commitment to preparing and training personnel. Not only will service, administrative and technical staff need to be oriented to their new roles and activities in the family support program, but parents and families too, could benefit from specialized training and support.

Evaluating Family Support Programs

Family support programs present unique challenges to professionals regarding the development of evaluation mechanisms to monitor activities, measure program outcomes, and provide direction for service improvement. Current efforts to evaluate the efficacy of family support services are plagued by two problems: 1) variation in program objectives, and 2) methodological problems.

Varying program objectives. Though there is little disagreement that the three goals of family support services are to enhance the family's caregiving capacity, to prevent unnecessary out-of-home placement, and to return persons living in out-of-home placements back to the home setting, there is a striking lack of consensus regarding what specifically these programs should accomplish, and how program objectives should be realized. The resulting variation in program objectives and administrative practices impedes efforts to evaluate existing programs because the use of standardized outcome measures is inhibited and programs cannot easily be compared.

Methodological problems. Methodological difficulties involved in the measurement of program processes and outcomes include:

- The insensitivity of measures to program effects: Due to the nature of developmental disabilities, service benefits are not always easily or promptly observed. Consequently, Halpern (1984) suggests that current measures may underestimate program effects. Moreover, Weiss (1983) notes that intervention efforts centering on the entire family require that measures be capable of monitoring changes within family dynamics. Such measures have yet to be perfected.

- The absence of longitudinal evaluation: The lack of immediately observable program effects also suggests that evaluation models should be designed to view change over time. Longitudinal evaluation, however, is burdened by a variety of difficulties, including the attrition of participating families, keeping service packages received by families constant, and determining the proper statistical means for assessing change over time (Cronbach & Furby, 1970).

- Sampling related problems: Halpern (1984) notes a variety of sampling-related problems including small sample sizes, the difficulty in employing random assignment of families to service groupings, and variability in the characteristics of families and persons with disabilities.
- Mitigating circumstances: Evaluation efforts can be adversely affected by a variety of uncontrollable circumstances. For example, Tausig (1983) and Herman (1983) note that several states have initiated policies whereby out-of-home placement into institutional settings is actively discouraged. The obvious impact of such policies on parental placement decisions greatly complicates the process by which family support programs are evaluated.
- Inadequate causal models: Due to many of the problems noted above it is extremely difficult to employ group-based research techniques within a causal model. Consequently, the effectiveness of family support strategies remains largely untested in a quantitative sense.

  An effective alternative strategy involves use of single subject design methodology to establish cause-effect relationships. This type of design generates information at a slower rate than group designs because it utilizes few subjects per study. It is, however, especially suited to coping with research problems where there is great variance in program objectives and practices.

These issues not withstanding, knowledge amassed through systematic program evaluation will be necessary to promote improvements in service delivery and to justify future levels of investment in family support programs. Though nearly 25 states operate what may be termed "extensive" family support programs, surprisingly few of these programs have been evaluated. At least two types of evaluation are possible: process and outcome. Process evaluation is generally used to improve the efficiency, responsiveness or relevance of an existing program, especially during its early stages of development. In contrast, outcome evaluation is designed to present conclusions regarding the overall effects or worth of a program, and often includes recommendations about whether it should be retained, modified, or eliminated.

The evaluation of family support services can take numerous directions given the complex interactions among family service needs, resources available to program planners, service process, and service outcomes. A sampling of the many areas of inquiry that evaluation of family support service might take includes:

- What is the relationship between the needs of families and persons with disabilities? What client needs (e.g., daily insulin injections, special diets, reducing maladaptive behavior) can be best accommodated by meeting certain family needs (e.g., specialized information and education)? What client needs are best met by professionals outside the family home and which are best met by family members?

- How are client and family needs related to the service delivery process? Are certain administrative practices (e.g., cash subsidies) more responsive to some service needs than others? What role should the private sector play in service delivery?

- What administrative practices are most time or cost efficient? Should cash subsidies utilize sliding fee schedules? How should services provided by multiple agencies be monitored and coordinated?

- What types and levels of service should be made available? How can specific family needs be identified? How can the type and level of services provided to families be determined?

- How do services affect a family's capacity to provide care? How are family dynamics altered? How do services affect the family structure, its functions, and its lifecycles? Do services really enhance the family's caregiving capacity?

- What are the outcomes of service delivery? Are cost savings realized by the state? Are parental placement decisions altered? Is the quality of life of individual families improved? Are families satisfied with services provided? To what extent do services satisfy the needs of families?

- What is the relationship between specific service delivery processes and program outcomes? Do certain administrative practices make a difference? Do certain services have a greater impact than others?

Of course, it will take several years to collect sufficient information to answer these and other relevant questions. However, the intention of evaluation is to develop a growing understanding of how to maximize the positive effects of family support programs.

Although to date, very few evaluations of family support programs have been undertaken, some data have been generated (See Agosta & Bradley, 1985). It is apparent that much of the qualitative evidence that has been collected documents the efficacy of family services. Families indicate that they appreciate such services, and are satisfied with their effects, including a reduction in levels of stress (Herman, 1983; Rosenau, 1983; Zimmerman 1984). Further, families report that they benefit most when they are provided with multiple service options (e.g., respite care, financial assistance and parent education) and least when they are offered fewer services (e.g., respite care only) (Moore et al., 1982). This suggests that no single service component is sufficient for achieving the goals of family support, but that several may be necessary.

The quantitative evidence is less conclusive. Much additional work must be done to gain a greater consensus regarding specific program objectives and to acquire sufficiently sophisticated evaluative measures and models. With these developments the effects of support services on the caregiving capacity of families and their placement decisions can be determined more definitively. Moreover, existing services can be modified so that they are matched more effectively to the service needs of individual families.

In sum, there is a tremendous need to evaluate existing family support programs. Such evaluation is desirable for two reasons. First, families who are or soon will be receiving services stand to benefit from improved administrative practices and an enhanced understanding of how to increase their caregiving capacity. Such findings may be translated into favorable program outcomes.

Second, evaluation findings could be used to spur increased investment in family support programs. Ultimately however, such investment must be based on a sound understanding of family needs. While evaluation can play a role in these decisions, the weight of the responsibility lies with advocates of all kinds who must convince policy makers that all concerned parties stand to benefit from the systematic application of family support services:

- The family benefits because of an enhanced capacity to provide care and an improved quality of life. Moreover, for some parents, receiving support services obviates any need for seeking alternative placement for their child or makes it possible for them to bring their child home from such placements;
- The person with developmental disabilities benefits because he or she is able to stay in a supportive home with more capable caregivers; and
- The state benefits because it has strengthened the family structure and may realize some cost savings due to a diminished need to fund expensive alternative residential options.

Moreover, arguments for family-based care should be translated into effective public policy that (1) reflects a fundamental respect for the potential caregiving capacity of the family and (2) provides sufficient funding to guarantee an adequate array of services.

PART TWO:

SUPPORTING FAMILIES IN VIRGINIA

Part One provided an overview of the conceptual underpinnings of family support programs and described the current status of such programs around the country. The second portion of this report builds on this information and offers a specific plan for the creation of a family support program in the Commonwealth of Virginia. The first section of this part describes the results of a survey of families with members with developmental disabilities in the state. The survey collected information on the characteristics of both the family and the family member with disabilities, the services that families are currently receiving, and the families' perception of the type of assistance they need but are not receiving.

The second section describes the proceedings of a two-day conference sponsored by the Virginia Department of Mental Health and Mental Retardation and the Human Services Research Institute on family support issues in Virginia. Participants at the conference, which was held in Lynchburg, Virginia in August 1985, included family members, persons with disabilities, professionals, state agency representatives and researchers. The purpose of the conference was to develop the outlines of a plan for a family support program in Virginia.

The final section recommends a plan for implementing a series of family support demonstration projects in Virginia. The plan is based on the consensus developed at the Lynchburg meeting, the results of the family survey and on lessons learned in other states.

THE NEEDS OF FAMILIES: RESULTS OF A STATEWIDE SURVEY IN VIRGINIA

John Agosta, Valerie Bradley, Anne Rugg,
Susan Covert, and Shirley Ricks

The presence of a person with a developmental disability in the home can present the family with a variety of extraordinary challenges. Though problems related to the provision of care sometimes prompt parents to seek an out-of-home placement for their offspring with disabilities, most reject such placements in favor of continuing family care (Perlman, 1983). This care often is provided with little external support and with great difficulty. In response, several states have implemented programs to support family efforts (Agosta, Jennings & Bradley, 1985; Bates, 1985). The primary goals of these programs are: 1) to deter unnecessary out-of-home placement, 2) to enhance the caregiving capacity of families, and 3) to make it possible for families to choose to have their disabled member return home from an out-of-home placement.

Following the lead of these states, Virginia is considering initiating its own family support program. The design of such a program, however, must be predicated upon an understanding of the varying needs of caregiving families. In this light, the purpose of this paper is to present the findings of a recent survey of caregiving families in Virginia. Information is provided on the characteristics of families and their members with disabilities, and the various needs of these families. Moreover, factors affecting the placement preferences of families are examined.

Method

Approach Taken

Information was gathered from families across Virginia who have a member with a developmental disability living at home. The survey process was completed in three steps: 1) design of the survey form, 2) design of a sampling plan and distribution of the survey forms, and 3) compilation of the information collected.

Design of the survey form. Design of the survey form was guided by a literature review, and the preferences expressed by the project's advisory committee and persons in Virginia. Six basic areas of inquiry were identified and 45 questions were written to secure information related to the target areas or domains. (Appendix 4 contains a copy of the survey form.) Several of these questions were based on a survey completed recently by Tausig (1985). Descriptions of the six domains and the types of questions included within each are as follows:

- family information: this section included seven questions concerning the characteristics of caregiving families (e.g., household composition, employment status of family members, family income, and sources of family income);
- information on the family member with a disability: this section included eight questions concerning the characteristics of the family member with a developmental disability (e.g., age, sex, disability type(s), and level of functioning). Families having members with disabilities younger than three years were not asked questions pertaining to the person with disabilities' behavioral competence or capacity to perform activities of daily living;
- information on family needs: this section included 21 likert scaled items designed to check the level of family need in a variety of areas. Scores on each item were summed to yield a "total family need" score;
- information on special costs to the family: this section included five questions. The first four concerned costs incurred by the family during the previous two years that were related to providing care (i.e., costs for adaptive equipment,

home barrier removal, medical/dental services, and other extraordinary services). Dollar amounts noted by families were summed to yield a "total special costs score." The fifth question pertained to the "opportunity" costs incurred by families, such as the cost of not taking a job, turning down a promotion or transfer, or losing a job due to the demands of providing care;

- information on external supports: this section included three questions. The first two requested information on the services received by the family member with disabilities. The third requested that membership with any advocacy or self-help group be noted.
- information on family placement preferences: this section included one question. Families were asked to note whether or not they had applied for, were planning to apply for, or were considering an out-of-home placement. In addition, families inclined toward an out-of-home placement were asked to specify their reasons.

Sampling plan and survey distribution. Crucial to any survey is its sampling plan. Ideally, the persons responding to a survey will, when considered together, be representative of the entire target population. Given restricted funds, a limited number of survey forms (n=420) and the absence of an existing list of caregiving families, no random sampling of the target population was possible, prompting use of a purposive sampling technique.

Purposive sampling is characterized by the use of judgement and a deliberate effort to select sample members that are representative of the population. In this case, the target population was considered families throughout Virginia providing home care to persons with developmental disabilities of all ages.

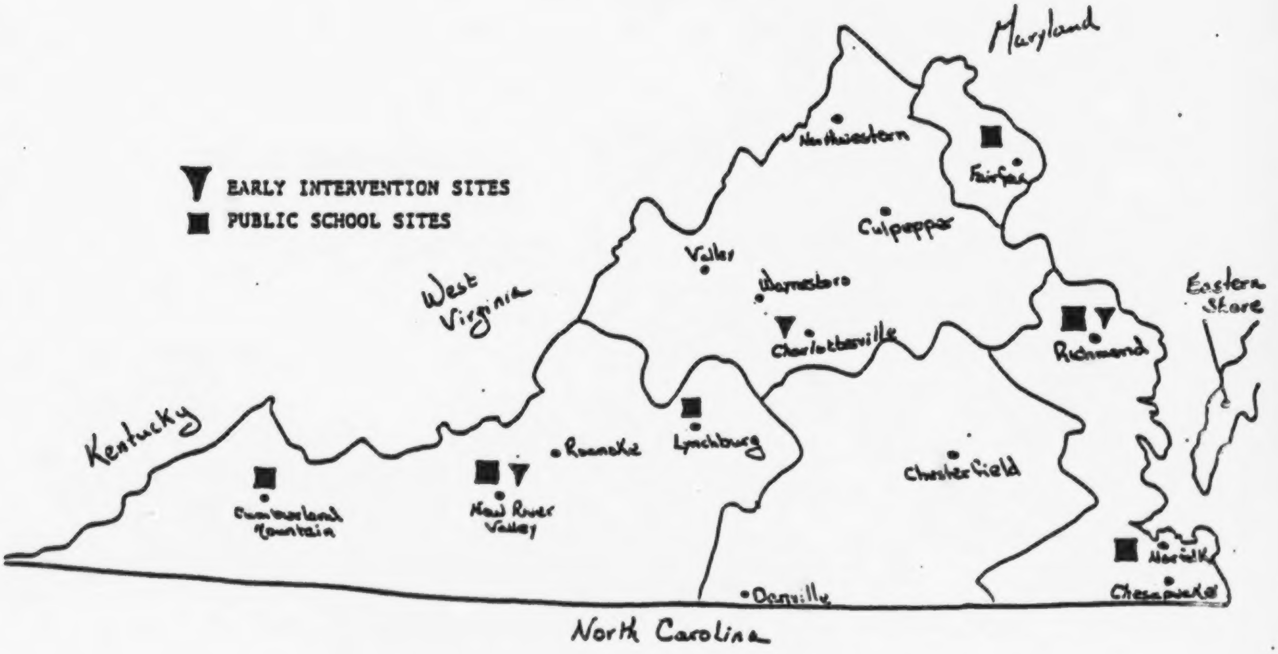
The lack of consensus regarding the ages of those with a developmental disability greatly complicated the matter of allocating survey forms for various age groups. To survey families of persons with developmental disabilities attending early intervention programs and public schools (ages 0-21), ten persons involved with services for this age group agreed to help with the distribution process. To assure a wide geographic distribution of survey forms, these persons were selected, in part, according to their area of residence.

The ten "site coordinators" were each sent a letter thanking them for their help and advising them of the distribution process (e.g. directions for distributing survey forms across age groups), and a set number of prepared envelopes. The contents of these envelopes included: 1) a letter describing the project, 2) one survey form, and 3) a prestamped and addressed envelope for respondents to return completed questionnaires. Subsequently, the site coordinators mailed the packets to families known to be providing home care. A total of 271 survey forms were distributed in this way. Figure 1 shows each of the distribution sites along with the number of survey forms distributed from each site.

To survey families of adults with developmental disabilities, a mailing list of families who participated in a previous study conducted by the Reseach and Training Center in Mental Retardation at Virginia Commonwealth University was used (Hill, Seyfarth, Orelove, Wehman & Banks, 1985). The study employed a stratified cluster sampling technique to assure ample representation of parents around the state. Staff at VCU provided a list of about 200 names resulting from the study, from which 149 were drawn at random. These families were mailed packets identical to the ones sent parents of those with disabilities attending early intervention and public school programs.

Compilation of returned information. Each of the 420 forms was precoded to track return patterns and to simplify the data compilation process. The codes could not be used to identify individual families.

Figure 1: Visual Display and Listing of Survey Sites


Maryland
Northwestern
Fairfax
▼ EARLY INTERVENTION SITES
■ PUBLIC SCHOOL SITES
Culpepper
Valley
Waynesboro
West Virginia
Charlottesville
Eastern Shore
Richmond
Kentucky
Roanoke
Lynchburg
Cumberland Mountain
New River Valley
Chesterfield
Norfolk
Chesapeake
Danville
North Carolina

Survey Site	Number of Forms Sent
Richmond area early intervention	10
Radford area early intervention	10
Charlottesville area early intervention	10
TOTAL:	30
Lynchburg area schools	44
Manassas area schools	44
Norfolk area schools	44
Radford area schools	44
Richmond area schools	45
Tazewell area schools	20
TOTAL:	241
OVERALL TOTAL THESE SITES:	271

Returned questionnaires first were screened to assess whether the information could be used. Completed survey forms were removed from further consideration if: 1) the person for whom the form was completed did not have a developmental disability, 2) numerous questions were left unanswered or responses could not be understood, 3) the family no longer provided home care, or 4) the family surveyed was providing subsidized foster care to the person with disabilities. In all, 38 survey forms were eliminated from subsequent analyses. Following initial review, information on those forms considered valid was coded and prepared for statistical analysis.

Response Rate and Limitations

The number of families returning survey forms deemed acceptable totaled 231, a response rate of 55%. Figure 2 is divided into two parts and displays the pattern of survey forms by age group and survey site. Though it is difficult to estimate the age distribution of persons with developmental disabilities living in the community, review of existing studies on the matter suggests that the pattern of valid survey forms might be skewed toward adolescents and young adults. In contrast, each survey site seems adequately represented, suggesting that respondents are generally representative of families throughout the state.

All told, however, it must be understood that a purposive sampling technique is not a substitute for random sampling. Moreover, mail surveys are vulnerable to error related to potential differences between those who choose to respond to the survey and those who do not. Consequently, survey findings may be biased in ways not readily observed and should be interpreted with caution.

Figure 2: Pattern of Returned Survey Forms

Age Group	Number of Valid Returns	Percent Valid Returns
0-5 years	36	16%
6-21 years	113	49%
22 and older	82	35%

Survey Site	Number of Forms Sent	Valid Returns	Percent Valid Returns
Richmond early intervention	10	4	40%
Radford early intervention	10	8	80%
Charlottesville early inter	10	6	60%
TOTAL:	30	18	60%
Lynchburg area schools	44	27	61%
Manassas area schools	44	20	45%
Norfolk area schools	44	23	52%
Radford area schools	44	19	43%
Richmond area schools	45	29	66%
Tazewell area schools	20	10	50%
TOTAL:	241	128	53%
Adults throughout Virginia (from VCU mailing list)	149	85	59%
OVERALL TOTAL:	420	231	55%

Results

The analysis was completed in two steps. First, frequency statistics were compiled regarding each of the primary information areas defined earlier. Second, factors related to the placement preferences of families were examined.

Frequency Statistics Regarding Six Primary Informational Areas

Information on Family Characteristics. Figures 3-6 present frequency statistics on the total sample regarding: 1) household composition, 2) employment status of family members, 3) presence of another person in the home with a disability, 4) total family income, and 5) sources of additional family financial support.

Selected Findings:

- The number of persons per household, excluding the family member with a disability, ranged from 0-10 and averaged 2.2;
- The number of families having a mother present totaled 208 (90%), while the number having a father present totaled 160 (69%);
- The age of caregiving mothers ranged from 21-78 and averaged 43.8 years. In contrast, the age of caregiving fathers ranged from 23-80 and averaged 46.5 years.
- While 125 families had no other children living at home, 31 had children at home aged 0-5 years, 41 had children aged 6-10, 48 had children aged 11-15, and 32 had childen at home aged 16 or over.
- The employment status of each household was examined by granting each person in a household two points for holding a full time job and one point for holding a part time job. Subsequently, points were summed for each household to yield a "total employment status" score. These scores ranged from 0-7 and averaged 2.16 per family.
- 39 families (16.8%) noted the presence of a person with a disability living at home other than the person for whom the questionnaire was completed.
- Regarding income, 155 (67%) families noted a total family income of less than $30,000 per year. A sizeable number (n=50 or 21.6%) noted annual incomes of less than $10,000.
- 100 families (43.5%) noted sources of income other than paying jobs. The number of additional sources was summed for each family to yield a "total financial assistance score." These score ranged from 0-4 and averaged .52 per family.

Figure 3: Summary Statistics Regarding Household Characteristics

VARIABLE	n	Number	Range	Average
Total number in the household	231	--	1-10	3.2
Presence of a mother	230	208	--	--
Mother's age	208	204	21-78	43.8
Presence of a father	230	160	--	--
Father's age	160	156	23-80	46.5
Total number of children	230	105	0-8	.76
Children aged 0-5 years	230	30	0-3	.16
Children aged 6-10 years	230	40	0-2	.19
Children aged 11-15 years	230	47	0-3	.24
Children aged 16 and under	230	104	0-8	.76
Children aged over 16	230	31	0-3	.16
Others in the household	230	71	0-4	.43

Figure 4: Employment Status of Family Members

Family Member	n	Number Missing	Full Time	Part Time	Not Employed
Mother	208	2	52	36	118
Father	160	3	126	5	26

Overall employment status per household was calculated by:

1) granting each person in the household two points for holding a full time job and one point for holding a part time job. and

2) summing points earned for each family.

Total Employment Status Scores: ranged from 0-7, and averaged 2.15/family.

Figure 5: Total Family Income

Income Category	Number of Families
$0 - $9,999	50
$10,000 - $19,999	55
$20,000 - $29,999	50
$30,000 - $39,999	33
$40,000 - $49,999	19
$50,000 or more	8
Missing Cases	16

Figure 6: Sources of Financial Assistance Other than Employment

Form of Assistance	Number of Families
NONE (no forms of financial assistance)	131
Other Forms	6
Aid for Dependent Children (AFDC)	10
Auxiliary Grant	0
Child Support/Alimony	15
Food Stamps	19
General Relief	3
Pension/ Rail Road or Veterans Benefits	9
Private Disability Insurance	0
Social Security	54
Unemployment Insurance	0
Missing Cases	7

Information on the person with disabilities. Figures 7-9 present summary statistics regarding the person's: 1) age, 2) sex, 3) disability type, 4) receipt of federal benefits (i.e., SSI, SSDI), 5) functioning level in five areas (mental development, physical development, behavioral competence, capacity to perform daily living skills, and need for special medical services), and 6) a "total functioning score" that represents the sum of responses to questions pertaining to functioning level.

Selected Findings:

- The age of family members with a disability ranged from under a year to 64 years and averaged 17.9 years;
- 132 (57%) of those living at home were male.
- The number of disabling conditions per person ranged from 1 to 6 and averaged 1.74. About half (49%), however, had but one primary disability.
- The most often noted disabling condition was mental retardation (n=174 or 75.3%), while cerebral palsy (n=50 or 21.6%) was noted second most often;
- For persons aged 0 to 18 years, 36 of 126 persons (28.6%) received either SSI or SSDI or both. For persons aged over 18 years, 90 of 104 persons (86.5%) received either SSI or SSDI or both.
- The majority of persons with disabilities living at home (n=174 or 83.3%) exhibit no or occasional behavioral incompetence, while 35 families (16.7%) note moderate to extreme behavior problems;
- The range of "total functioning level" scores ranged from 1-15 (highest possible score is 15) and averaged 7.5.

Figure 7: Demographic Characteristics of Family Members with a Developmental Disability

AGE:

Range: Under a year to 64 years old
Average: 17.9 years
Missing Cases: 1

SEX:

Number of Females: 98
Number of Males: 132
Missing Cases: 1

DISABILITY TYPE:

Disability Type	Number of Persons
Don't know	1
Autism	10
Cerebral Palsy	50
Developmental Delay	10
Downs Syndrome	18
Emotional Disturbance	15
Epilepsy	30
Hearing Loss	16
Mental Retardation	164
Muscular Dystrophy	2
Physical Disability (other than listed)	29
Spina Bifida	5
Vision Loss	17
Other Disability Than Those Listed	25
Missing Cases	1

Number of Persons with One Primary Disability: 118
Number of Persons with Multiple Disabilities: 113
Missing Cases: 1

Number of Disabilities per Person:
range: 1-6
average: 1.74

Figure 8: Level of Functioning in Five Areas

Area		Level of Impairment			
	# of Missing	Little or No	Some	Moderate	Extreme
Mental Development	21	5	33	94	78
Physical Development	21	46	49	63	50
Medical Impairment	15	71	56	66	23
Behavior Problems	22	94	80	19	16
Capacity for Performing Daily Living Skills	22	75	36	13	85

For persons aged three years and over responses on questions concerning functioning level were scored from 0 to 3 (0 indicating little or no impairment and 3 indicating extreme impairment).

Total Functioning Level Scores:

ranged from: 1 to 15
averaged: 7.6

Figure 9: Number of Persons Receiving SSI or SSDI By Two Age Groups

	Age Group			
	0 thru 18 (n=126)		Over 18 (n=104)	
Federal Benefit	No	Yes	No	Yes
SSI	92	34	28	76
SSDI	122	4	68	36
SSI OR SSDI	91	33	14	68
SSI AND SSDI	123	3	82	22

Information on family needs. Figure 10 presents summary statistics on the family's need for: 1) information, 2) assistance in providing direct care, 3) additional specialized services for the person with disabilities, and 4) social interaction. In addition, responses to 19 of the 21 family need questions were summed to yield a "total needs score." (Items 5 and 13 on Figure 10 were not included in the scale score because they were not deemed applicable to caregiving families with children aged 0-3 years.) Figure 11 displays a comparison (using t-tests) of needs noted by families whose disabled member is 21 years and under with families whose disabled member is over 21 years.

Selected Findings:

- For many of the needs listed, significant numbers of familes noted "little or no need."
- The least noted needs were transportation and home barrier removal (See Figure 10). The need with the highest apparent magnitude concerns information on future financial planning. Review of family need scores, however, reveals significant variance in the type and level of family needs.
- The "total needs score" for the entire sample ranged from 0-74 (highest possible score is 76) and averaged 25.29.
- Families with disabled members aged 21 and under indicate a higher level of need on all scale items but one; the exception pertains to the need for recreational opportunities (See Figure 11).
- Review of the level of need expressed by families in the two age related groups reveals statistically significant differences on 14 of the 20 items on the family needs scale (See Figure 11).

Figure 10: Frequency Statistics Regarding Family Needs

	NO NEED 1	2	3	4	EXTREME NEED 5	MISSING
1. Information on the type of disability my disabled family member has	123	31	42	11	20	4
2. Information on how or where to get services . . .	83	36	44	21	43	4
3. Information on how to best care for my disabled family member	102	40	40	17	27	5
4. Information on planning for the future financial welfare of my disabled family member.	37	24	49	27	93	1
5. Information on how to deal with behavior problems displayed by my disabled family member	84	40	27	14	41	25*
6. People who can come to my house and help me care for my disabled family member on short notice. .	108	23	24	16	57	3
7. Qualified persons to care for my disabled family member overnight	104	17	35	22	51	2
8. Other families with a disabled child with whom I can talk to about raising my disabled. . . . family member	120	39	31	12	25	4
9. A place where my disabled family member can go during the day while I do something else. . like go to work, school or shop	122	19	25	17	45	3
10. Time to complete household chores or routines (shopping, house cleaning...)	142	18	30	13	23	5
11. More time just for myself	104	23	39	11	49	5
12. Specialized services for my disabled family member like speech or physical therapy . . .	86	25	42	27	46	5
13. More opportunities for recreation for my disabled family member like bowling, ... swimming, dancing, or summer camp	77	27	28	26	50	23*
14. Money to use to care for my disabled family member	98	31	29	18	51	4
15. Temporary relief from caring for my disabled family member.	109	26	28	18	44	6
16. A way to transport my disabled family member around town when needed	177	7	18	5	18	6
17. Special equipment for my disabled family member (like arm or leg braces, a wheelchair, . special shoes or toys)	159	12	19	14	22	5
18. Modifications to our house to make it easier for my disabled family member to get around. . (like grab bars, ramp, wider doorways)	181	8	17	4	17	4
19. Medical insurance that covers more of the cost of medical care for my disabled family member .	110	17	29	10	61	4
20. Doctors who understand how to care for my disabled family member.	95	23	37	23	49	4
21. Dentists who understand how to care for my disabled family member.	118	21	23	15	51	3

* Note: Families with children in early intervention programs (n=30) received survey forms lacking these questions.

Figure 11: Differences in Family Needs by Age Group

	21 AND UNDER (n=148) MEANS	OVER 21 (n=81) MEANS	t-TEST	# MISSING CASES
1. Information on the type of disability my disabled family member has	1.14	.75	2.20*	5
2. Information on how or where to get services	1.76	1.26	2.39*	5
3. Information on how to best care for my disabled family member	1.31	1.05	1.37	5
4. Information on planning for the future financial welfare of my disabled family member.	2.63	2.26	1.75	2
5. Information on how to deal with behavior problems displayed by my disabled family member	1.64	1.13	2.37*	26
6. People who can come to my house and help me care for my disabled family member on short notice. .	1.67	1.24	1.87	4
7. Qualified persons to care for my disabled family member overnight	1.71	1.26	1.99*	3
8. Other families with a disabled child with whom I can talk to about raising my disabled. . . . family member	1.25	.63	3.45***	5
9. A place where my disabled family member can go during the day while I do something else. . like go to work, school or shop	1.50	.95	2.54**	4
10. Time to complete household chores or routines (shopping, house cleaning...)	1.13	.50	3.65***	6
11. More time just for myself	1.84	1.09	2.51**	6
12. Specialized services for my disabled family member like speech or physical therapy . . .	1.85	1.29	2.57**	6
13. More opportunities for recreation for my disabled family member like bowling, ... swimming, dancing, or summer camp	1.64	1.85	-.91	24
14. Money to use to care for my disabled family member	1.91	.80	5.65***	5
15. Temporary relief from caring for my disabled family member.	1.50	1.12	1.71	7
16. A way to transport my disabled family member around town when needed	.66	.45	1.22	7
17. Special equipment for my disabled family member (like arm or leg braces, a wheelchair, . special shoes or toys)	1.10	.23	5.53***	6
18. Modifications to our house to make it easier for my disabled family member to get around. . (like grab bars, ramp, wider doorways)	.70	.24	3.13**	5
19. Medical insurance that covers more of the cost of medical care for my disabled family member .	1.77	1.11	2.89**	6
20. Doctors who understand how to care for my disabled family member.	1.71	1.38	1.50	5
21. Dentists who understand how to care for my disabled family member.	1.54	1.10	1.97*	4

- Note: Families with children in early intervention programs (n=30) received survey forms lacking these questions.

- * p < .05
  ** p < .01
  *** p < .001

Information on special costs. Figure 12 presents: 1) summaries of the special dollar costs incurred by families over the past two years, and 2) findings regarding the opportunity costs incurred by families.

Selected Findings:

- Regarding special dollar costs, the majority of families note no extraordinary costs related to special equipment (77.9%), home barrier removal (91.7%), medical services (58.8%), or other special services (83.1%).
- The majority of families (54.8%), however, note at least one type of special dollar cost. For these families, when special costs are summed across all cost categories, costs range from $40 to $106,799 and averaged $6,319 per family (median equals $1,100).
- 141 families (61%) noted no opportunity costs related to the provision of care, while 34 (14.7%) noted that a family member had to give up a paying job, 46 (19.9%) had not taken a job, and 25 (10.8%) had refused a job transfer or promotion. When opportunity costs were summed to yield a "total opportunity cost" score, the scores ranged from 0-3 (highest possible score is three) and averaged .42 per family.

Figure 12: Special Costs Incurred by Families

DOLLAR COSTS:

Type of Cost	Number Missing Cases	Number with Costs	Range	Average	Median
Special Equipment	1	50	$40-6,300	$1,173	$420
Housing Modifications	1	18	$40-6,000	$1,361	$400
Medical/Dent Services	1	84	$25-10,000	$1,274	$600
Other Costs	1	38	$61-100,000	$17,583	$1,500

Special Dollar Costs for families indicating some type of cost were summed to yield a Total Dollar Cost Score.

range of total dollar costs: $40 to $106,799
average total dollar costs: $6,319
median total dollar costs: $1,100

OPPORTUNITY COSTS

Type Cost	Missing Cases	Number of Families Noting an Occurrence
Given up a paying job	22	34
Not taken a paying job	24	46
Refused a job transfer or promotion	23	25

Instances of Opportunity Costs were summed per family to yield a Total Opportunity Cost Score.

Range: 0 to 3
Average: .42 per family

Information on services received. Figures 13 and 14 display service utilization patterns for services received by the person with disabilities and family members. In addition, Figure 15 summarizes the self-help or advocacy groups survey with which respondents hold memberships.

Selected Findings:

- 31 of a total of 77 persons (40%) aged over 21 years were not in a sheltered work program;
- Review of Figures 14 suggests that, on balance, families receive relatively few services to support their efforts;
- About half (n=115 or 49.8%) of those families surveyed did not belong to an advocacy or self help group. Of those that do, the most often noted membership is with the Association for Retarded Citizens (n=78 or 33.7%). Membership with various parent to parent groups is noted second most often (n=21 or 9%).

Figure 13: Services Received by the Family Member with a Disability By Age Group

	Age Group					
	0 thru 21 (total n=148)			over 21 (total n=82)		
Service	Yes	No	% Yes	Yes	No	% Yes
Early Intervention/Preschool	35	105	25%	0	73	0%
Special Education	111	33	77	18	55	25
Regular School	11	110	9	1	72	1
Sheltered Work Program	3	119	2	46	31	60
Physical Therapy	64	75	46	3	70	4
Speech or Hearing Therapy	78	60	56	8	65	11
Counseling	9	111	7	16	57	22
Recreation Program	37	101	27	23	50	32
Mobility Training	17	120	12	5	68	7
Other	10	127	7	7	66	10

Figure 14: Services Received by the Family By Age of Disabled Family Member

	Age Group					
	0 thru 21 (total n=148)			over 21 (total n=82)		
Service	Yes	No	% Yes	Yes	No	% Yes
Day Care	19	123	13%	3	70	4%
Homemaker (home health aide)	2	140	1	2	72	3
Counseling	10	132	7	11	64	15
Respite Care or Sitter Service	33	109	23	5	69	7
Training in Parenting Skills	9	133	6	2	72	3
Behavior Consultation	9	133	6	7	67	9
Other	7	135	5	3	71	4

Figure 15: Membership with Advocacy or Self Help Groups

Organization	Number of Families
NONE --No Memberships	115
Missing Cases	15
Association for Retarded Citizens (ARC)	78
United Cerebral Palsy (UCPA)	8
Society for Autistic Children	2
Epilepsy Foundation of America	2
Parent to Parent network group	21
Other	22

Information on placement preferences. Figure 16 presents summary statistics related to the present placement preferences of families. In addition, for those families considering an out-of-home placement (n=69), Figure 16 also offers frequencies on the several reasons offered for such plans by two age groupings.

Selected Findings:

- The majority of families (n=156 or 67.5%) note no plans to seek an out-of-home placement. Of those that do, 43 report that they are merely considering the option, eight note that they plan to apply for placement, and 18 report that they already have; and
- Reasons noted for an out-of-home placement vary by age of the family member with a disability. Generally, parents of older persons (older than 21 years) note reasons suggesting that the disabled person is old enough to live away from the family home. In contrast, parents of younger persons (0-21) note problems related to an inability to meet the habilitative needs of the disabled person and a need for relief from the provision of care.

Prediction Models Regarding Placement Preferences

Family situations are not static but evolve as family members age and pass from one life stage to the next (Konanc & Warren, 1984). This suggests that factors influencing family placement preferences will vary with the age of the family member with disabilities and his or her caretakers.

Figure 16: Family Placement Preferences

THE QUESTION:

Are you planning to request that your disabled family member be placed in a living arrangement outside your home in the near future (0-3 years)? (For example, to a foster or group home, state residential facility or institution) (CHECK ONLY ONE)

18 YES, our family has already applied for an out-of-home placement and we are waiting to hear about our status

69 — 8 YES, our family is planning to request an out-of-home placement

43 DON'T KNOW YET --our family is discussing this issue but we have not decided on what to do

156 NO, our family has no plans to seek an out-of-home placement

REASONS GIVEN BY 69 FAMILIES:

	DD Persons Aged 0-21 (n=35)	DD Persons Aged over 21 (n=34)
disabled person wants to live somewhere else (eg., group home, own apartment)	3	9
disabled person could live away from home on his or her own	4	7
disabled person is old enough to live with others his/her own age	9	17
disabled person needs more care than the family can provide	13	8
disabled person has severe medical problems that cannot be met at home	2	0
disabled person has behavior problems that cannot be controlled	10	5
disabled person has special needs that the family is unable to afford	6	1
need to devote more time to other family members	15	2
disruption of family life	11	10
family has legal problems	1	0
death or illness of primary family caretaker	5	7
doctor or other professional(s) have advised placement	8	4
can't get needed services in the home	9	4
Other reasons	7	5

Regarding home care, one key transition period is the graduation from the public school system (around age 18-21). Consequently, following the lead of Tausig (1985), the sample was divided into two groups based on the age of the family member with disabilities: 1) persons aged 21 and under, and 2) persons aged over 21 years.

Analytic Approach. The identification of factors related to family placement preferences was achieved in two steps. First, zero order correlations of each study variable with stated placement preferences were calculated for each age group. This tactic confirmed the importance of dividing the sample because it showed that the factors influencing placement preferences varied by age group. It addition, it provided a basis for subsequent multivariate analyses.

The multivariate approach employed was multiple regression. Specifically, a stepwise regression procedure was used, allowing comparison of the relative contribution of various independent variables to the prediction of a preselected dependent variable while also controlling for any intercorrelation among the predictor variables. In addition, it sums the unique contributions of each predictor to yield an equation that includes the most powerful predictive factors.

Correlations with Placement Preferences. Figure 17 displays zero order correlations of selected variables with placement preferences and shows that:

- The patterns and strength of relationships vary across age groups. There are more statistically significant correlations within the 0 to 21 group than within the 21 and older group, suggesting that the dynamics regarding placement preferences are more complex within younger families. Also of interest is the significant negative correlation (r=-.27) in the 21 and older group between the presence of another person in the household with a disability and placement preference.

Figure 17: Correlations of Selected Variables with Family Placement Preferences for Two Age Groups

	AGE GROUP	
VARIABLE	DD Persons Aged 0 thru 21 (n=146) (SEE NOTE 1)	DD Persons Aged Over 21 (n=78) (SEE NOTE 1)
Total number in the household	.120	.142
Mother in the family	-.066	-.066
Mother's age	.156 (n=131)	.064 (n=66)
Father in the family	.019	.032
Father's age	.292** (n=98)	.052 (n=54)
Number children at home	.100	.081
Children aged 0-16	.103	.058
Children aged over 16 years	.324***	.159
Another at home with a disab	.112	-.279**
Household employment status	.206**	.016
Total family income	.200*	.233*
Age of person with disability	.302***	.150
Sex of person with disability	-.045	-.190
Number of disabling conditions	.182*	.006
Level of mental impairment	.343***	.201
Presence of behavior problem	.227**	.287**
Total Functioning Level Score	.173	.183
Need temporary relief	.335***	.348**
Need day care	.200*	.149
Need recreational opportunities	.219* (n=124)	.272*
Need information (SEE NOTE 2)	.267**	.306**
Need qualified help (SEE NOTE 3)	.318***	.235*
Need trained dentists	.066	-.047
Need trained doctors	.148	.092
Total Need Score	.218**	.236*
Special dollar costs	-.002	.128
Opportunity costs	-.041	.047
Receipt of SSI or SSDI	.024	.020
Number of client serv received	.125	-.118
Number of family serv received	.173*	.142
Total number services recd	.196*	-.039
Membership in an advocacy group	.120	.124

Note 1: * $p < .05$
** $p < .01$
*** $p < .001$

Note 2: "Need information" was calculated by summing 4 items in the total needs scale. These items pertain to: 1) how or where to get services, 2) how to care for the disabled person, 3) future financial planning, and 4) how to deal with problem behavior.

Note 2: "Need qualified help" was calculated by summing two items in the total needs scale. These items pertain to: 1) finding people to provide respite, and 2) finding qualified people to provide overnight respite.

Perhaps, some older persons with developmental disabilities play a useful role in caring for others with disabilities in the family, reducing interest in an out-of-home placement; and

- Six variables are significantly correlated with placement preference regardless of age group, including total family income, the presence of a behavior problem, and the need for temporary relief from careprovision, more recreational opportunity for the disabled person, information and for qualified persons to assist with direct care.

Based on these findings, certain variables with the highest correlation with placement preferences for each age group were selected for subsequent regression analyses. Figures 18 and 19 display these variables for each age group along with their intercorrelations. Though the correlations displayed in these figures are generally low, some are high enough to suggest that certain variables explain overlapping portions of the total variation in placement preference.

Regression analyses regarding persons aged 21 and under. Given the variety of variables correlated with placement preferences for this age group, five separate regressions were undertaken. These regressions were based on literature suggesting that placement preferences are related to client characteristics, family characteristics, the amount of stress or burden on the family, and the amount of support received by the family (Sherman & Cocozza, 1984; Tausig, 1985). The top portion of Figure 20 displays results of four regressions pertaining to these areas and shows that, considered separately, variables in each of the areas explain some portion of the total variation regarding placement preferences. These results, however, show some of the stronger predictors to be: the number of children at home aged over 16 years, level of mental impairment, the presence of a behavior problem, age of the person

Figure 18: Intercorrelations Among Selected Variables
by Age Group (Persons Aged 0 through 21)

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Father's Age	X														
2. Children Aged Over 16	.24**	X													
3. Household Employ Status	-.14	.07	X												
4. Total Family Income	.03	-.04	.53***	X											
5. Age of Disabled Person	.60***	.17*	-.11	-.05	X										
6. Number of Disab. Condit.	-.01	-.06	-.10	-.04	.16*	X									
7. Level of Ment Impairment	.15	.07	.09	.06	.16*	.27***	X								
8. Presence of a Behav Prob	.11	-.06	.09	.16*	-.06	.10	.20**	X							
9. Need for Temporary Relief	.07	-.02	.03	.08	.12	.20**	.22**	.26**	X						
10. Need for Day Care	.01	.00	.01	-.08	.08	.07	.18*	.16*	.52***	X					
11. Need for Recreat Oppor.	.07	-.08	.03	.08	.12	.01	-.08	.11	.33***	.21**	X				
12. Need Information	.01	-.04	.04	.05	.08	.15	.16*	.28***	.44***	.31***	.43***	X			
13. Need Qualified Help	.01	.00	-.01	.04	.07	.25***	.27***	.26**	.56***	.59***	.24**	.39***	X		
14. Total # Serv Received	-.10	-.06	.21**	.18*	-.24**	-.07	.30***	.22**	.22**	.17*	.09	.27**	.19*	X	
15. Placement Preference	.29**	.32***	.21**	.20**	.30***	.18**	.34***	.23**	.34***	.20**	.22**	.27**	.32***	.20*	X

* :p < .05
** :p < .01
*** :p < .001

Figure 19: Intercorrelations Among Selected Variables
by Age Group (Persons Aged Over 21)

Variable	1	2	3	4	5	6	7	8
1. Another at Home with a Disab.	X							
2. Total Family Income	-.18	X						
3. Presence of a Behavior Prob.	.12	.03	X					
4. Need for Temporary Relief	-.10	-.14	.38***	X				
5. Need for Recreational Oppor.	-.07	.00	.39***	.52***	X			
6. Need for Information	.04	-.06	.64***	.59***	.72***	X		
7. Need for Qualified Help	-.04	-.06	.21	.63***	.52***	.53***	X	
8. Placement Preference	-.27**	.23*	.29**	.35**	.27*	.31**	.23*	X

* :p < .05
** :p < .01
*** :p < .001

with disabilities, and the family's need for temporary relief from the provision of care.

The bottom portion of Figure 20 shows results of the fifth regression. This regression analysis includes all those variables that were used in the previous four regressions. The resulting "combined equation" suggests the relative importance of all the variables considered and explains 31.7% of the total variation in placement preferences. Key predictors include: the level of mental impairment, the presence of children at home over age 16, and the need for temporary relief and increased recreational opportunity for the person with disabilities. The restricted number of variables included in the combined equation reflect the intercorrelation or overlap of the variables considered.

Regression analyses regarding persons over age 21. As shown through review of zero order correlations, the variables related to placement preferences for this age group differ in type and number from those identified for persons aged 21 and under. In fact, the few significant correlations preclude calculation of several regression equations. Consequently, one regression analysis was undertaken that included all previously selected variables for this age group. The resulting "combined equation" is displayed in Figure 21 and explains 23.8% of the total variation in placement preferences. Key predictors include: the need for temporary relief, family income, and the presence of another person with a disability in the household (Note that the correlation of this final variable with placement preference is negative).

Figure 20: Regression Analyses Concerning Family Placement Preferences (21 and Under)

REGRESSIONS BY VARIABLE CATEGORY:

Category: Family Characteristics

Variable	Beta^{a}	Multiple R	R^2	R^2 Change
Children at home 16 and above	.244**	.324	.105	.105
Father's Age	.265**	.392	.154	.048
Household Employment Potential	.226**	.451	.204	.049
Total Family Income	This Variable Not Entered Into The Equation for Statistical Reasons.			

Category: Characteristics of the Disabled Person

Variable	Beta^{a}	Multiple R	R^2	R^2 Change
Level of Mental Impairment	.259**	.343	.117	.117
Age of the Disabled Person	.272***	.424	.180	.062
Presence of a Behavior Prob	.192*	.464	.215	.035
Number of Disabling Conditions	This Variable Not Entered Into The Equation For Statistical Reasons			

Category: Perceived Level of Family Needs

Variable	Beta^{a}	Multiple R	R^2	R^2 Change
Need for Temporary Relief	.229*	.335	.112	.112
Need for Qualified Help	.188	.369	.136	.024
Need for Day Care Need for Recreational Oppor Need for Information	These Variables Were Not Entered Into The Equation For Statistical Reasons			

Category: Services Received

Variable	Beta	Multiple R	R^2	R^2 Change
Total Services Received at Home	.196*	.196	.038	.038

COMBINED EQUATION:

Variable	Beta^{a}	Multiple R	R^2	R^2 Change
Level of Mental Impairment	.288**	.343	.117	.117
Children at home 16 and above	.322**	.456	.207	.089
Need for Temporary Relief	.210*	.532	.283	.075
Need for Recreational Oppor	.197	.563	.317	.033
Father's Age Household Employment Potential Total Family Income Age of the Disabled Person Number Disabling Conditions Presence of a Behavior Prob Need for Day Care Need for Information Need for Qualified Help Total Services Received at Home	These Variables Not Included In The Equation For Statistical Reasons			

a: Coefficients are standardized

** : $p < .01$
* : $p < .05$

Figure 21: Regression Analysis Concerning Family Placement Preferences (Over 21)

Variable	Beta-a	Multiple R	R^2	R^2 Change
Need for Temporary Relief	.362**	.348	.121	.121
Total Family Income	.249*	.450	.202	.081
Presence of Another Disabled Person	-.194	.488	.238	.035
Presence of Behavior Problem Need for Recreational Oppor Need Information Need Qualified Help	These Variables Not Entered Into the Equation for Statistical Reasons			

a: Coefficients are standardized

** : $p < .01$
* : $p < .05$

Discussion

Research has long documented the habilitative needs of persons with developmental disabilities. Only recently have concerted efforts been made to examine the varying needs of families choosing to provide care at home. Regarding family needs, this study suggests that:

- There is a wide range of family needs. Survey results confirm that families can have multiple needs spanning several domains including information, assistance in providing direct care, specialized services for the person with disabilities, and social networking. Additionally, results show that families cannot be thought of in terms of an "aggregate average." Families function as unique caregiving units, sharing some needs but, having needs that are particular to the characteristics of the person with disabilities and the caregiving resources of the family;
- The need for support is enduring. Survey results show that regardless of the age of the person with disabilities, families generally have a need for some type of support; and
- Family needs evolve as the family unit ages. Though the need for support is enduring, family needs are not static but evolve as the family unit passes from one life stage to the next. Study results suggest that:

* In comparison to older families, younger families generally have a greater and more diverse need for support;

* A crucial time for many families occurs as siblings of the person with disabilities reach ages where they naturally part from the family. The loss of these previously dependable caretakers reduces the family's capacity to provide care and places a greater portion of the burden on parents who are themselves growing older; and

* As family members age, there is an increased recognition that family care of all types ends eventually and that the same holds true for persons with disabilities. Many parents of persons with disabilities aged over 21 who are inclined toward an out-of-home placement reason that their disabled adult is old enough and often capabable enough to live away from the natural home.

Considered together, these observations suggest that policy designed to support families should:

- Provide families with multiple service options. Because no two persons with developmental disabilities or two families are alike, responsive family support programs must make available to families a wide array of services and encouage each family to select those services that are most appropriate to its needs;

- Provide families with timely and long term support. The need for support services does not begin or end at some arbitrarily set date. Rather, support services must be available to families from the onset of disability to the time the person with disabilities leaves the natural home;

- Be especially responsive to the need of young families and families with extraordinary caregiving responsibilities. Establishing eligibility criteria is a perplexing issue that severely tests a society's capacity for equitably distributing scarce resources to those in need. Survey results, however, suggest that family support systems should be especially responsive to families of persons with disabilities aged under 21 and to families providing care to persons with severe levels of impairment or whose needs pose an extraordinary challenge to the family; and

- Work in tandem with policy designed to foster development of community based residential alternatives to the family. Because all familiy care ends eventually, family support policy should not be premised upon an expectation of continued home care. Rather, policy should be sensitive to a growing need for residential alternatives to the family, especially as the person with disabilities reaches adulthood.

Additionally, this study exemplifies the need for further examination of factors influencing the family's caregiving capacity and placement preferences. Though this study confirms previous findings regarding the diversity of family needs and the variables affecting placement (eg., Tausig, 1985), too little is known about how supports can be used to promote and enhance home care. Future research must eventually include analyses of existing family support systems for purposes of improving service delivery practices and spurring increased investment in family support.

THE VIRGINIA FAMILY SUPPORT CONFERENCE: PROCEEDINGS AND FINDINGS

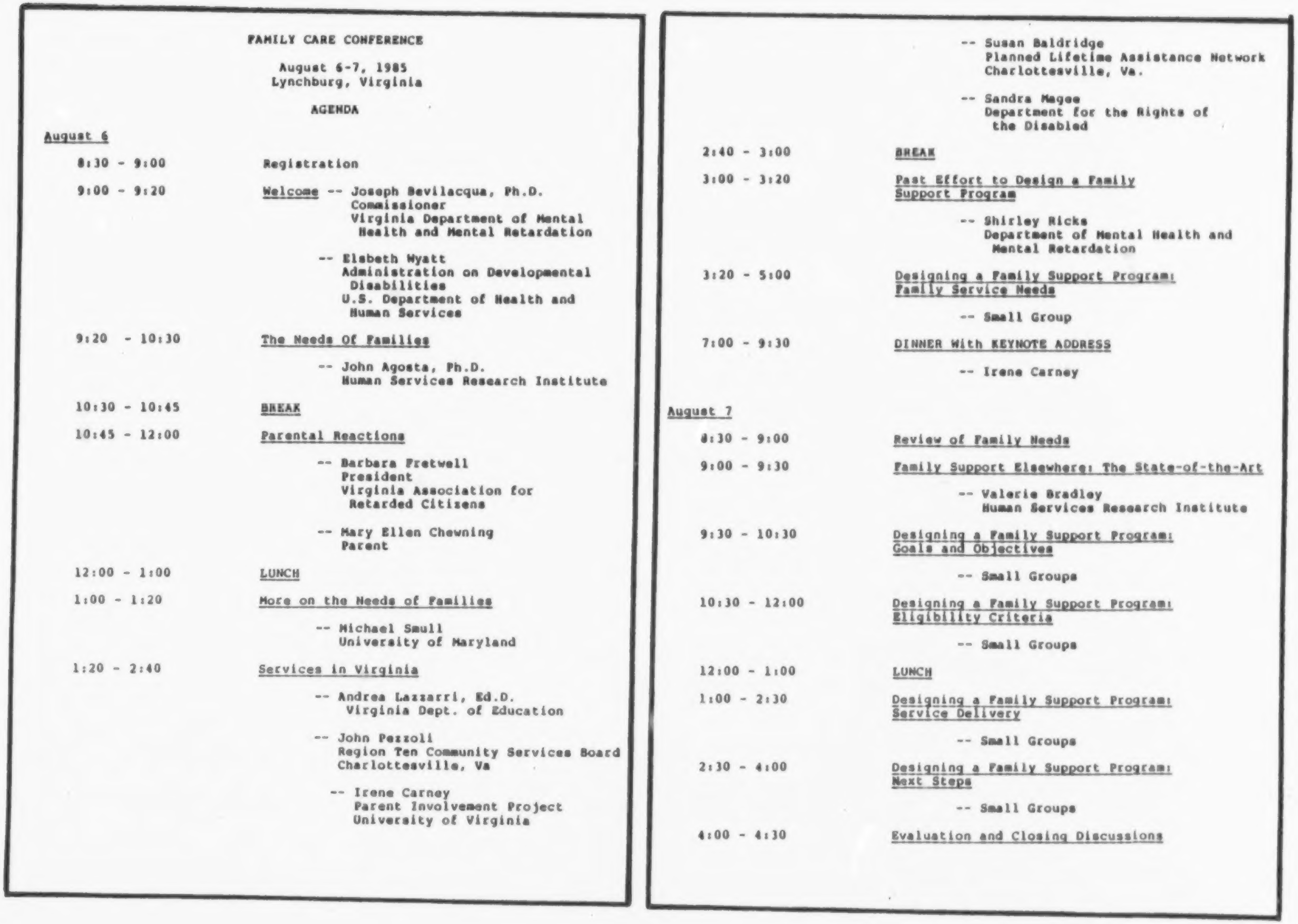
On August 6-7, 1985 a conference concerning family support policy was held in Lynchburg, Virginia. Nearly 100 persons attended the conference, representing parents, persons with disabilities, government officials, service providers and administrators, and concerned advocates (See Appendix 5 for a list of conference participants). The objectives of this conference were: 1) to present project findings and to gain a better understanding of the policy preferences of Virginians, and 2) to solicit the participation of a wide range of individuals in the development of a family support program for the Commonwealth. The following section provides highlights of the conference.

Approach Taken

The family support conference was conceived as a "participatory planning process." This approach invites participants representing various key interests to work together to reach a common understanding of a particular problem and to negotiate a solution. Figure 1, the agenda for the Lynchburg meeting, shows that this aim was achieved in two steps: 1) presentation of technical information by staff and sharing of personal experiences by family members, and 2) conduct of multiple issue resolution sessions.

Technical Information and Experience Sharing

Before asking participants to consider the design of family support policy, it was important to provide them with information regarding the nature of the problem, what can be done about it, and the impact of present policy on the lives of individuals with



FAMILY CARE CONFERENCE

August 6-7, 1985
Lynchburg, Virginia

AGENDA

August 6

8:30 - 9:00	Registration
9:00 - 9:20	Welcome -- Joseph Bevilacqua, Ph.D. Commissioner Virginia Department of Mental Health and Mental Retardation -- Elsbeth Wyatt Administration on Developmental Disabilities U.S. Department of Health and Human Services
9:20 - 10:30	The Needs Of Families -- John Agosta, Ph.D. Human Services Research Institute
10:30 - 10:45	BREAK
10:45 - 12:00	Parental Reactions -- Barbara Fretwell President Virginia Association for Retarded Citizens -- Mary Ellen Chewning Parent
12:00 - 1:00	LUNCH
1:00 - 1:20	More on the Needs of Families -- Michael Smull University of Maryland
1:20 - 2:40	Services in Virginia -- Andrea Lazzarri, Ed.D. Virginia Dept. of Education -- John Pezzoli Region Ten Community Services Board Charlottesville, Va -- Irene Carney Parent Involvement Project University of Virginia -- Susan Baldridge Planned Lifetime Assistance Network Charlottesville, Va. -- Sandra Magee Department for the Rights of the Disabled
2:40 - 3:00	BREAK
3:00 - 3:20	Past Effort to Design a Family Support Program -- Shirley Ricks Department of Mental Health and Mental Retardation
3:20 - 5:00	Designing a Family Support Program: Family Service Needs -- Small Group
7:00 - 9:30	DINNER With KEYNOTE ADDRESS -- Irene Carney

August 7

8:30 - 9:00	Review of Family Needs
9:00 - 9:30	Family Support Elsewhere: The State-of-the-Art -- Valerie Bradley Human Services Research Institute
9:30 - 10:30	Designing a Family Support Program: Goals and Objectives -- Small Groups
10:30 - 12:00	Designing a Family Support Program: Eligibility Criteria -- Small Groups
12:00 - 1:00	LUNCH
1:00 - 2:30	Designing a Family Support Program: Service Delivery -- Small Groups
2:30 - 4:00	Designing a Family Support Program: Next Steps -- Small Groups
4:00 - 4:30	Evaluation and Closing Discussions

Figure 1: Family Support Conference Agenda

disabilities and their families. Such information, in turn, prompted subsequent discussion based on a common set of referents, shared knowledge of the state-of-the-art, and a sensitivity to real life experiences.

Following welcoming statements, project staff, and presenters from Virginia and Maryland provided conference participants with information concerning: 1) the needs of families, 2) services already available in Virginia to accommodate such needs, and 3) the nature of family support initiatives in other states. During these presentations, conference participants were encouraged to share their personal experiences on these matters.

The Needs of Families

To begin, project staff presented the results of a literature review concerning family needs and of the statewide survey of caregiving families in Virginia described in the previous section. As shown in Figure 2 below, the literature suggests that families and their members with a developmental disability can have a variety of needs.

Figure 2: List of Required Services

Home-Based Services Centered Around the Person with Disabilities	Services Centered Around Family Members
adaptive equipment	information and referral
educational/therapeutic services	temporary relief/respite
transportation	family counseling
medical or dental services	parent/sibling education
home barrier removal	homemakers
special clothing	chore services
special diets	housekeepers
diagnosis and assessment	cash assistance
medication	future financial planning
home health care	
attendant care	
recreational services	

To a great extent, the statewide survey confirms these findings and suggests, additionally, that:

- Families cannot be thought of in terms of an "aggregate average." Families function as unique caregiving units, sharing some needs, but with needs that are particular to the characteristics of the person with disabilities and the caregiving resources of the family;
- The need for support is enduring. Regardless of the age of the person with disabilities, families generally have a need for some type of support; and
- Family needs evolve as the family ages. Though the need for support is enduring, family needs are not static but evolve as the family passes from one life stage to the next. Specifically, study results show that: 1) in comparison to older families, younger families generally have a greater and more diverse need for support, 2) a crucial time for many families occurs as siblings of the person with disabilities reach ages where they naturally part from the family, reducing the family's capacity for providing care, and 3) as family members age, there is an increased recognition that home care cannot be provided indefinitely, prompting concern over the future well-being of the family member with a disability.

Following presentation of these findings, participating parents were invited to share their personal experiences to enrich and/or correct the information provided. Leading these discussions were Barbara Fretwell, president of the Virginia Association for Retarded Citizens (VARC), and Mary Ellen Chewning, former president of VARC. These parents recounted the challenges they face daily, and argued that parental emotional reactions to the discovery of disability should not be labeled as "adverse" or "positive" but simply should be accepted. As one parent put it, "leave us our emotions."

Other parents shared the frustrations they encountered in attempting to secure needed services or benefits. For instance, it was noted that some parents who wanted to attend the conference could not because they were unable to find someone to stay with their family member. One parent expressed particular dissatisfaction with federal Medicaid policy. He explained that his child has medical and physical impairments that are expensive to treat but that, because she is under 18 years of age, his income is deemed available to her, causing her to be ineligible for Medicaid benefits. As a result, he and his wife have incurred extraordinary medical expenses.

Other parents, who had long ago obtained an out-of-home placement for their family member with a disability, described the emotional turmoil that surrounded their decision and explained their acceptance of that decision. These parents reminded all of those present that family support should not be premised on the expectation that every person with disabilities can be maintained at home, but that parental choice regarding residential alternatives for their family member with a disability must be respected.

Finally, Michael Smull of the University of Maryland presented selected results of the Maryland Community Needs Survey (Black, Smull, Crites and Sachs; 1985). This effort examined the needs of persons with mental retardation living at home, in critical need of services, but receiving no services. Survey findings show a relationship between the stress experienced by caregiving families and the urgency of their need for services, including out-of-home placement. Such stress can be tied to a variety of factors including family characteristics (e.g., the capacity to cope with stress) and characteristics of the person with disabilities (e.g., presence of maladaptive behavior or medical problems, absence of self care skills). These findings suggest that though families may choose to provide home care, many do so under great stress that could be eased if they were provided with needed services.

Rounding out these discussions was an address delivered by Irene

Carney following dinner on the first night of the conference (Appendix 6 contains the full text of this speech). Ms. Carney asked participants to imagine three families providing home care, each facing different daily challenges. Based on descriptions of these families and on information presented earlier in the day, she noted that it is obvious that families throughout Virginia are committed to home care, but have a great need for help of some kind. She asked all to embrace the importance of building a partnership between professionals and families that allows professionals to exercise their skills to the benefit of the family, while families are not made to feel like "another bothersome statistic on someone's already heavy caseload." As a first step toward supporting families in Virginia, Ms. Carney urged that, as family members, we should extend ourselves to one another; as teachers, working to the limits of our skill, we should treat our students and clients with respect; and as professionals we should demonstrate to families that our work with them is not a necessary evil but a priority concern.

Services Available in Virginia

Though there are numerous needs among families in Virginia, it would be a mistake to assume that Virginia has done nothing to support families and establish community services. To describe services currently in place, conference organizers asked several agency representatives to make brief presentations. Initiatives discussed included:

- Early intervention through the Department of Education. Andrea Lazzari, representing Early Childhood Programs for the Handicapped, described the nature of early intervention programs operating around the state for children aged 2-5 years. These "center-based" programs provide specialized services to children with disabilities and, in some school districts, provide certain services to families. She noted that when devising policy, planning for a smooth transition for clients as they move between service systems must be considered. Additionally, she noted that the provision of public school services for students with disabilities has done much to support family efforts;

- Community Services Boards. John Pezzoli of the Region Ten Community Services Board described the community services structure and suggested that a good deal more must be done to expand and improve services. Among those services provided, several CSBs offer early intervention programs for children aged 0-3 years. The nature of these programs varies. Some programs are primarily home-based while others are center-based. Likewise, some provide services only for the child with disabilities, while others offer certain services to family members as well. He warned that though initiation of a family support system would be welcomed, it should not be designed to compete for funds with existing services, but should be made a part of the community services continuum.

- University Projects. Irene Carney of the Parent Involvement Project at the University of Virginia described a federally sponsored demonstration project. This project, funded from October, 1983 through October, 1986, assists families, who have members with severe to moderate handicaps, with the process of long term planning, especially with regard to key transition periods. Families can: 1) acquire information through a newsletter, 2) request individual consultation with project staff, or 3) participate in a parent-to-parent mutual help group. In addition, it was noted that universities can play a useful role in supporting families by: acting as informed advocates for persons with disabilities, obtaining federal dollars to undertake demonstration projects, providing state-of-the-art services and information (eg., diagnosis and evaluation), training practicing and future professionals, and helping to evaluate the effects of programs.

- Protection and Advocacy. Sandra MaGee, of the Department for the Rights of the Disabled, noted that the department is charged with ensuring, protecting and promoting the rights of persons with disabilities. Given some problem with finding or using services, the department, by federal law, must have the authority to pursue legal, administrative and other appropriate remedies. Specific individual services include: 1) information and referral, 2) legal advocacy to assist with the resolution of disputes, and 3) client assisted programs (CAPs) for the Departments of Rehabilitative Services and for the Visually Handicapped, and Independent Living Center programs.

- Future Financial Planning Susan Baldridge, representing the Planned Lifetime Assistance Network (PLAN), reported that planning for the future well-being of a person with disabilities can be a troubling task for many persons. PLAN has just received federal funding to help establish a statewide program to provide a variety of services designed to assist parents with planning for the financial and personal security of family members with developmental disabilities (It should be noted that a comparable effort, the Virginia Beach Trust Fund, is currently in operation.)

Following these presentations, Shirley Ricks, of the Department of Mental Health and Mental Retardation, reported on the recommendations of a earlier Family Support Task Force. The work of that task force resulted in a proposal by the Department for a pilot cash subsidy program to be included in the 1984-86 biennial budget. The characteristics of this program are displayed in Figure 3.

The proposed program did not receive sufficient legislative support for passage for a variety of reasons, including the absence of widespread support for the program among consumers and professionals, and the lack of familiarity with the idea. Consequently, conference participants were advised by Ms. Ricks not to be overly optimistic about the possibilities of swift legislative approval of a family support program. Rather, plans must be laid to generate support through coalition building among persons with disabilities, parents, advocates and professionals, and through systematic education of legislators. Additionally, Ms. Ricks advised that policy planners should be prepared to consider a support service approach instead of one based on a cash subsidy.

Family Support Elsewhere: The State-of-the-Art. Project staff provided the participants with information based on: 1) a 50 state survey conducted in collaboration with the National Association of State Mental Retardation Program Directors, and 2) visits by project staff to six states with "extensive" programs including Florida, Michigan, Ohio, Pennsylvania, Rhode Island and Washington. Some of the key findings shared with participants were:

Figure 3: Characteristics of a Pilot Cash Subsidy Program Proposed by the 1983 Family Support Task Force

- Program Type: Cash Subsidy disbursed as a reimbursement for incurred expenses (ie., a voucher system).

- Program Size: 25 to 100 persons at a total annual cost of $3,640 per person or $91,000 to $364,000.

- Goals and Objectives: There were five program objectives

  1. To enhance the ability of the family to cope with and care for the person with disabilities;
  2. Enhance the overall quality of life of the person with disabilities
  3. Better utilize generic services;
  4. Decrease the dependency of caregivers on financial aid in the future; and
  5. Decrease the need for institutionalization.

- Eligibility Criteria: Program eligibility was to be decided based on:

  1. Characteristics of the caregiver: Two types of caregivers could qualify for the program: a) natural, adoptive or foster care parents, or b) a parent sponsor;
  2. Characteristics of the person with disabilities: Three types of persons could qualify for financial assistance: a) those presently living in a state facility, b) those presently living in the community but at risk of being placed in a state facility, or c) those living in the community and in need of services;
  3. Screening Criteria: Use of a state screening committee was planned as a means of systematically allocating finite resources. Five considerations were noted: a) total family income, b) the cost of providing supplemental services to the person with retardation, c) the need for services, d) the eligibility of the applicant for other, already existing, support services, and e) the availability of insurance to cover the costs of needed services.

- Permissible Services: The types of service the cash subsidy could be used for included medical and dental services, respite care, educational services (for services not covered under PL 94-142), special equipment, recreation, transportation, special diets, and, upon review, certain unusual services.

- Service Administratiuon: The maximum support allowable was set at $300 per month per family. Families would be reimbursed for allowable services provided they could show receipts for their expenses. Procedures regarding means for auditing the program were also set. Continued reimbursement would be made contingent upon a quarterly review by the screening committee. In addition, rules were set to govern any move to terminate the program for specific families;

- Evaluation: Two evaluations of the program were planned, one at 12 months, the other at 24 months. These evaluations were to include an assessment of: the developmental growth of persons with disabilities in the program, program costs and effects, and the composition of the waiting list (if any).

- Though nearly all states report some type of family support program, fewer than 25 administer "extensive" programs;

- Most of these 25 programs were initiated after 1980 and serve relatively few families. However, the move to support families is gathering strength as several states are considering development or expansion of programs (e.g., Colorado, New York, Massachusetts, Oregon);

- Eligibility criteria varies by state. In general, criteria can involve any of three considerations: 1) characteristics of persons with disabilities (e.g., age, disability type, severity of disability), 2) characteristics of the family (e.g., total income, capacity to pay for services), and 3) status of the current placement (e.g., at risk of out-of-home placement, returning home from a state facility);

- Seven states provide free support services, eight states provide cash subsidies, and eight states provide some combination. A cash subsidy approach is preferred by many parents because it empowers them to select services that are most appropriate to their needs. Michigan is considered by many to administer a model subsidy program. In contrast, given the difficulty of tracking expenditures in a subsidy program, state officials often prefer a support service approach;

- Three crucial program design issues pertain to the role of the family in directing services, eligibility criteria, and what services will be provided or deemed permissible;

- Fewer than five states have conducted systematic evaluations of their programs;

- Family support proponents face many barriers including: 1) the attitudes of some professionals who presume familial incompetence and favor provision of services outside the family home, 2) the belief of many that caregiving families are soley responsible for child rearing and public dollars should not be provided in their support, 3) administrative uncertainties regarding program costs and effects, and 4) continued funding patterns that are biased in favor of services outside the home; and

- Key to the development of family support programs has been the pressure placed on policy makers by parents and concerned advocates, most notably through state Councils on Developmental Disabilities and Associations for Retarded Citizens.

Issue Resolution Sessions

The purpose of these sessions was to promote discussion among conference participants regarding several policy issues. For each problem, participants were divided into three groups, and instructed to discuss the issue and reach consensus regarding its nature and/or resolution. In all cases, results of small group interactions were presented to the total group to: 1) identify similarities and differences in thinking between groups, and 2) promote negotiation directed at reaching consensus within the total group. Three primary areas of concern included: the service needs of families, program design specifications, and future courses of action.

The Service Needs of Families

Conference participants were asked to reach consensus regarding the service needs of families (i.e., the nature of the problem). Participants were assigned to one of three groups: parents, state officials, and service providers. Persons not fitting into any of these groups were invited to join the group of their preference.

Though each group approached the problem from a different perspective, there was general agreement between groups, resulting in little need for negotiation. The list of service needs is shown in Figure 4 and is divided into four categories based on the age of the person with disabilities: 1) service needs common to families of persons of any age group, 2) services for families of children aged 0-5 years, 3) services for families of persons aged 6-21 years, and 4) services for families of persons aged over 21 years. Given this list, the goal of subsequent issue resolution sessions was to design a program that could accommodate most, if not all, identified needs.

Program Design Specifications

Three program design issues were addressed: 1) What should the goals of the program be?; 2) Who should be eligible for services?; and 3) How should services be delivered?

Figure 4: List of Family Service Needs Compiled by Conference Participants

Service Needs Common to All Ages

1. Case advocacy and Management
2. Temporary/Periodic Relief
3. Crisis Stabilization
4. Transportation
5. Attendant/Personal Care
6. Home Barrier Removal
7. Counseling
8. Parent Education
9. Parent Self-Help Groups
10. Recreational Opportunity
11. Medical Insurance
12. Genetic Counseling
13. Medical and Dental Services
14. Out-of-home Residential Options
15. Diagnosis and Evaluation
16. Advocacy
17. Specialized Therapies
18. Behavior Consultation
19. Money for Special Items
20. Continuous (transition) Planning
21. Education for Professionals
22. Training Teams
23. Adaptive Equipment
23. Information on:
    - available service options
    - various disabilities
    - medical insurance
    - available federal/state benefits
    - future financial planning

Service Needs (0-5 Years)

1. Parent Counseling
2. Structured Day Care
3. Referral to CSBs
4. Infant stimulation
5. Prepare for transition to public schools
6. Training for staff at neo-natal units

Service Needs (6-21 Years)

1. Day Care
2. Summer Work Experience
3. Sex Education
4. Guradianship/Trust
5. CSB Casemanagement
6. Improved School Curricula

Service Needs (Adults)

1. Habilitative Training
2. Vocational Training
3. Geriatric Services
4. Community Skills Training
5. Support for Parents with Disabilities
6. Increasing Participation of Dept. Rehab. Services

What should the program goals be? Conference paticipants agreed on the following eight program goals:

1. To improve the quality of life of persons with disabilities and their families through provision of direct services and by strengthening the family's capacity to provide care;

2. Prevent unnecessary out-of-home placement;

3. Make it possible for families to choose to have their member with disabilities return home from a state facility;

4. Expand the nature and availability of community services to caregiving families;

5. In partnership with professionals, empower families to direct the course of services received;

6. To ensure the protection of the rights of persons with disabilities;

7. Foster greater coordination of services throughout the life of persons with disabilities; and

8. Foster increased public awareness of the needs of families and their members with disabilities.

Who should be eligible for services? Given finite resources, deciding on program eligibility requirements is a complex issue that defies easy solution. Not surprisingly, the topic provoked lively discussion that revolved around five considerations: 1) "disability type" (e.g., mental retardation, developmental disabilities, chronic mental illness, frail elderly), 2) characteristics of the person with disabilities (e.g., age, severity of disability), 3) characteristics of the family (e.g., total income), 4) placement status (e.g., returning home from an out-of-home residence, in danger of such placement), and 5) criteria for choosing cases with the highest priority.

Finally, it was generally agreed that families would be eligible for family support services, if:

1. a family member has a condition that is consistent with the definition of "disability" set forth in Virginia House Bill 817. This bill specifies that a person with disabilities means any person who has physical or mental impairments which substantially limits one or more of his major life activities or has a record of such impairment. This definition is expanded within the bill in sections pertaining to employment, education, public accommodation, and housing. It should be understood that the definition of disability used in HB 817 is stated in terms broad enough to include persons who are not clients of the Department of Mental Health and Mental Retardation;

2. the person with disabilities lives in the home of a parent (natural or adoptive) or parent sponsor (adult relative or interested person who has been appointed guardian with the responsibilities of full or limited guardianship);

3. the caregiving parent or parent sponsor is a Virginia resident;

4. the needed services cannot be obtained at no charge from some other source.

Additionally, anticipating that more families would be deemed eligible for services than the program could accommodate, a system of review of individual cases was recommended. The system would require establishment of "local review boards," composed of parents and professionals, that would identify cases having the greatest need for services. Though judgements would likely vary some by board, decisions would be based on an appraisel of:

1. the severity of disability -- the more severe the disability, the greater the need for support services;
2. family fiscal resources in relation to the costs of needed services -- the less capable a family is to pay for needed services, the greater the need for support services;
3. family characteristics -- the fewer caregiving resources a family has (e.g., alternate caregivers, single parent household), the greater the need for support services; and
4. urgency of need -- to a point, the greater the risk of out-of-home placement, the greater the need for support services. The program, however, should not embrace a "crisis intervention" role, rushing in to support families only as the home placement is near collapse. Though a certain amount of crisis intervention is inevitable, the program also must be used to prevent crises.

How should programs be delivered? Devising specific means of service delivery was beyond the scope of this conference. In providing general guidelines for program design, however, conference participants strongly recommended that the program first be designed as a pilot project. It was argued that a pilot project would have greater political feasibility, give program proponents time to muster support for a larger effort, and allow time to evaluate and improve on service delivery practices.

Regarding design guidelines, it was recommended that the program:

1. Embody a spirit of family empowerment, whereby family members, in partnership with professionals, are encouraged to take an increasing role in directing the course of the services they receive;

2. Be administered as a "combination program" that would offer families:

   * certain services free of charge. These services would include those that all families need to improve their understanding of the challenges they face and to prepare them for an increased role in directing the course of the services they receivce. Examples of such "core services" include information and referral, diagnosis and evaluation, and parent education; and

   * a cash subsidy used to reimburse families for certain service related expenses. A reimbursement strategy was chosen based on the need for program accountability. Families would be reimbursed after submitting an invoice for expenses. Whether families would have to show receipts for specific expenses was left open to discussion.

   Moreover, recognizing that family needs can differ, conference paricipants favored a system that allowed families to use their subsidies to purchase services or materials that were "related to the provision of care." However, to ensure accountability, it was recommended that: 1) a list of "permissible services" be drawn up, 2) the list be fairly comprehensive, providing families with "multiple service options," and 3) means be established for considering requests for spending subsidies on unusual services;

3. Provide families with a "case consultant." The case consultant would help the family prepare its own Individual Family Services Plan (IFSP), which would be updated monthly (at least initially). This plan would outline the support services the family requires, and how the family plans to spend its cash subsidy. With time, the family would be encouraged to prepare its own IFSP, subject to periodic review by the case consultant. Moreover, the case consultant would act as an advocate of the family, identifying and coordinating needed services;

4. Be administered through community services boards. Though the Department of Mental Health would act as chief funder, oversee the entire program, and set basic program standards, community service boards would be responsible for administering local initiatives. Specifically, community services board staff would be responsible for:

- Hiring and supervising family case consultants;
- Providing certain support services; boards may elect to have their own staff provide these services or have others render such services through a purchase of service contract;
- Disbursing and tracking cash subsidies;
- Establishing and maintaining a review board to examine individual cases with regard to program eligibility or termination;

5. Be evaluated for purposes of examining its costs and effects, and improving the means of service delivery; and
6. Make use of existing resources. Developing a family support system does not necessarily imply a need for establishing an entirely new and separate service system. Much can be done to build on existing resources. For instance, greater use can be made of public school facilities, community college campuses, community centers, church facilities, and other existing sites to serve as day care centers, recreational sites, or training centers for persons with disabilities or family members. Likewise, previously unused professional resources in the community and at universities can train staff and parents, provide direct care, and evaluate program effects.

Plan of Action

Amid a spirit of coalition building, conference participants issued four recommendations concerning a future course of action:

1. The proceedings and findings of this conference should be disseminated statewide through various advocacy groups, community services boards, and state offices;
2. A second Family Support Task Force should be established to design a pilot project in detail;
3 Staff from the Department of Mental Health should meet with representatives of key advocacy groups to establish a consensus position on the matter and a spirit of "joint ownership" of the pilot project. This initial meeting should be followed by a series of regional meetings with advocates, state officials, community service board staff, and sympathetic legislators in attendance to develop a plan for nurturing increased interest in supporting families;
4. Coordinated efforts should be initiated to make legislators more aware of the needs of families. This could be achieved through letter campaigns, petition drives, use of mass media, and face to face discussion with legislators. All agreed,

however, that such efforts must be well coordinated, perhaps through the family support task force or some coalition of advocacy groups.

Concluding Remarks

The family support conference provided an opportunity for persons concerned with supporting families to initiate the design of a family support program for Virginia. The recommendations emerging from the conference are recognized as preliminary and not fully comprehensive. They will require further consideration and refinement. They do, however, represent the consensus of a group of knowledgeable persons who devoted two days of serious thought and discussion on the matter.

Conference deliberations all revolved around the common belief that something more could and should be done in support of families and their members with disabilities. Subsequent discussion will be needed to assess the full implications of various recommendations, finalize specific design specifications for a pilot family support program, and set plans for generating needed legislative support. As in other states where successful family support programs have been mounted, the key to the success of these activities will be the active involvement of caregiving parents, persons with disabilities, and other concerned advocates, including professionals and state officials. It is hoped that these conference proceedings will help inform and encourage this process.

A PLAN FOR SUPPORTING FAMILIES: THE VIRGINIA FAMILY ASSISTANCE PILOT PROGRAM

This section presents a plan for initiating a pilot program for supporting Virginia families who have a member with disabilities living at home. The plan is based on the results of a federally-funded study that included a review of literature on family support, a national survey of similar initiatives in other states, a survey of caregiving families in Virginia, and on the recommendations of a statewide conference on family support held in Lynchburg in August, 1985.*

What is the Virginia Family Assistance Pilot Program?

The Virginia Family Assistance Pilot Program will provide systematic support to parents or parent sponsors who are responsible for providing home care to persons with developmental disabilities. The purposes of the program are to: 1) meet the special needs of persons with disabilities living at home, 2) strengthen the family's capacity to provide care, 3) prevent unnecessary out-of-home placement, and 4) make it possible for families to choose to have their family member return home from such placement.

The Family Assistance Program will begin to fill a void in present state policy by recognizing the need for support among families who have members with disabilities. While Virginia taxpayers pay for expensive out-of-home residential placements for persons with mental illness and developmental disabilities, the state provides little, if any, support to families who provide care at home. While not competing for funds with existing programs, the proposed family assistance pilot will provide an incentive for families to continue to provide less costly care at home and will improve the quality of such care.

---

* Note: This proposal differs in a few respects from the program that emerged from the participatory conference. Though most program options that were recommended at the conference are included in the proposal, some have been scaled down to fit within the constraints of a pilot program. We believe, however, that, on balance, the proposed plan captures the fundamental preferences of those who attended the conference.

Why Provide Families With Assistance?

The presence of a person with disabilities in the home can present the family with a variety of extraordinary challenges. For many families the initial recognition that a severe disability exists presents an immediate crisis that evolves into a life crisis. Families can experience chronic stress, extraordinary financial costs, lost opportunities for employment or career advancement, disrupted household routines, frustration due to a lack of knowledge about the needs of their family member, and the lack of needed community supports.

In addition, two other factors must be considered. First, the needs of persons with disabilities change over time as the individual progresses from one developmental stage to the next. Second, as parents grow older, their capacity for providing care changes, prompting concern over the future financial well-being of their adult with disabilities.

These considerations suggest that in addition to the direct care services persons with disabilities may receive outside the home (e.g., public education, vocational training, etc.), family members also need support services at home to ease the day-to-day demands of caring for a person with disabilities, and to enhance their capacity to provide care. Support services can have at least three positive effects:

- For many parents, receiving such services eliminates or delays the need for alternative placement for their son or daughter with disabilities or makes it possible for them to choose to bring their family member home from such placement;
- The person with disabilities is accorded an improved quality of life; and
- The state benefits because of a potentially diminished need to fund expensive alternative residential options.

A National and Statewide Perspective

Over 25 states have undertaken programs to support caregiving families, with several other states planning such initiatives. In great part, this trend reflects a growing recognition of the needs of families and of the need to alter federal and state fiscal policy that has favored out-of-home service options over family care.

While most states administer systems that provide families with support services, several others have adopted an innovative program design strategy that involves disbursement of cash subsidies to qualifying families. This alternative is premised on the belief that families are responsible caregivers and capable of making informed decisions about the services they require.

In Virginia, parents who provide home care increasingly are voicing their concern over the lack of services to support their efforts. Many consider the absence of such services to be unfair, especially when one considers that even a small decrease in family efforts would confront legislators, taxpayers, and residential service providers with enormous financial and administrative burdens. The proposed family assistance program would help rectify this imbalance and would establish a cost effective means for the state to support family efforts. Moreover, it would reinforce a growing resolve within the Commonwealth to recognize the crucial role families play in providing care to persons with disabilities.

The Virginia Family Assistance Pilot Program

The Family Assistance Pilot Program is designed to encourage the development of programs that are flexible enough to meet the varying needs of families and localities, yet structured enough to foster improvement in service delivery practices and to ensure cost accountability. To achieve these ends, the Family Assistance Pilot Program will require certain "core characteristics" that do not differ across programs, and will leave the remaining program design decisions to local areas.

In establishing a pilot project, the Department of Mental Health and Mental Retardation will request proposals from community services boards and will fund five demonstration programs -- one program for each planning region. The overall cost of the project will be $500,000, with each demonstration program being awarded $100,000. Each successful proposal will be premised on the following core characteristics:

- Program Orientation. Demonstration projects should reflect a spirit of "family empowerment," whereby family members, in partnership with professionals, are encouraged to take an increasing role in directing the course of the services they receive.

- Program Eligibility. A family shall be considered eligible for receiving services if:

    1. a family member has either mental retardation/developmental disabilities or mental illness and is a client of the Department of Mental Health and Mental Retardation. In general, persons with mental retardation/developmental disabilities have handicaps that originate during the developmental period and that are associated with impairment in adaptive functioning. Likewise, persons with mental illness are afflicted with mental disease to such an extent that for his or her own welfare or the welfare of others specialized treatment is required;

2. the person with disabilities lives in the home of a parent (natural, foster or adoptive) or parent sponsor (adult relative or interested person who has been appointed guardian with the responsibilities of full or limited guardianship);
3. the caregiving parent or parent sponsor is a Virginia resident;
4. the needed services cannot be obtained at no charge from some other source.

- Selecting Families for Receiving Services. Anticipating that more families would be deemed eligible for services than the program can accommodate, a system of review of individual cases will be needed. Such review will be undertaken by "local review boards," established by the community services board and composed of parents and professionals. The review board will select families for inclusion in the program by identifying the cases with the greatest need for services. Though judgements will likely vary some by board, priority consideration will be given to:

  1. persons under age 21 with severe and/or multiple handicapping conditions;
  2. persons with disabilities who are on waiting lists for admission to a state facility or for community services;
  3. persons with disabilities residing away from the family home, such as in a state facility, and whose parents would choose to provide care at home, if they were provided support services;
  4. families whose fiscal resources, in relation to the costs of needed services, are insufficient; and
  5. single parent families or other types of families with limited resources to provide care.

- Case Coordination. Participating community services boards will provide a "case consultant" to each family who is receiving services. The case consultant: 1) will be an employee of the community service board, 2) will act as an advocate for the family, identifying and coordinating needed services, and 3) will be responsible for helping the family prepare its own Individual Family Services Plan (IFSP). This plan will show what services the family is due to receive and has received, and will be updated monthly. With time, the family will be encouraged to prepare its own IFSP, subject to periodic review by the case consultant.

Local demonstration projects will also address programmatic specifications based on local circumstances. Options that should be considered include:

- Organizational Format. To administer family assistance programs at the local level, participating community services boards can choose among differing organizational formats. For instance, boards may choose to:

  1. deliver family support services by hiring their own staff;
  2. contract with local service providers to provide all family assistance services. Such arrangements may involve long term purchase of service agreements and/or utilization of specialized professionals on an ad hoc basis; or
  3. some combination of the options noted above.

- Means of Service Administration. Though the actual types and/or amounts of service delivered will be governed by the Individual Family Services Plan noted earlier, community services boards may choose among four service delivery options:

  1. Support Services Model: This approach provides families with materials or services;
  2. Cash Subsidy Model: This approach provides families with a pre-determined amount of money to offset care-related costs. Typically, the money is dispensed monthly and no documentation of spending patterns is required;
  3. Cash Voucher Model: This approach reimburses families with cash to offset care related costs. Money is disbursed only after families submit an invoice documenting their expenses along with receipts for purchases over some set amount.
  4. Combination Model: This approach involves use of some combination of the models noted above. Typically, a support services approach offering certain core services (e.g., information and referral, parent education) is coupled with a means of providing families with cash to pay for other needed services.

- Expense Limits Per Family. Given restricted budgets for the demonstration project, hard decisions must be made regarding how much money can be allotted to participating families. Community services boards may choose among at least these three program options:

1. Set no expense limit per family: Recognizing that family needs can change dramatically, this option sets no arbitrary limit on the amount that can be spent per family. Instead, families are evaluated frequently and are allocated an expense limit commensurate with their circumstances and needs. As a result, individual family limits can flucuate and program coordinators must keep close track of their overall program expenditures;

2. Set an upper limit on expenses: Like the approach above, this tactic recognizes that family needs differ and calls for frequent review by the case consultant. It does, however, set an upper limit on the amount that can be spent per family. The limit can refer to expenditures per family per month or over the course of a service year; or

3. Set an expense limit for all families: This approach does not allow variations in expense limits, but sets an arbitrary limit that pertains to all families. It assumes that participating families all have roughly the same magnitude of need and does not require frequent review of family needs and circumstances. The limit can refer to expenditures per family per month or over the course of a service year.

- Permissible Services. No two families or two persons with disabilities are alike. Consequently, the types of services deemed permissible must be flexible enough to provide families with "multiple service options." To satisfy the demands of program accountability, however, community services boards must be able to document that program expenditures are directly related to the care of the person with disabilities. There are two ways to achieve such accountability:

  1. In collaboration with local parents, program administrators can devise a list of services that will be offered and/or deemed permissible for parents to receive. If this approach is chosen, however, a system of review also must be established to consider requests for unique services not on the list; or

  2. Families, in collaboration with the case consultant, can decide which services they require. Services chosen, however, must be related to the provision of care.

Program Evaluation

Evaluation of the Virginia Family Assistance Pilot Program is necessary to provide direction for program improvement and to justify continued investment in family care. An annual evaluation of the five demonstration projects will be required to provide the Governor, legislators, and other concerned parties with:

- Descriptive information regarding the families and the persons with disabilities who participated in the five demonstration programs, as well as those on waiting lists for family support services.
- An assessment of the impact of the program on families and persons with disabilities compared to outcomes for those who did not receive services;
- An assessment of the differences in costs and effects associated with each of the five demonstration programs;
- An assessment of the extent to which programs achieved their goals;
- An assessment of family satisfaction with the program; and
- Recommendations for programmatic or legislative action to further assist families who are providing care to persons with disabilities.

To evaluate the Virginia Family Assistance Program, the Department of Mental Health and Mental Retardation should choose either to: 1) use its own in-house evaluation team, or 2) contract with an outside group, possibly a university. The latter course has the advantage of enhancing the objectivity of the results. Further, by taking advantage of the expertise available at various universities in the state, the Department could forge a valuable collaboration in the area of family support.

APPENDIX ONE:

COMPOSITE BIBLIOGRAPHY

COMPOSITE BIBLIOGRAPHY

Agosta, J.M. & Bradley, V.J. (Eds.) Family care for persons with developmental disabilities: A growing commitment. Boston, MA: Human Services Research Institute, 1985.

Apolloni, A.H. & Triest, G. Respite services in California: Status and recommendations for improvement. Mental Retardation, 1983, 21, 240-243.

Ashbaugh, J. & Allard, M. Comparative analysis of the costs of residential and day services within institutional and community settings. Boston, MA: Human Services Research Institute, 1983.

Ashbaugh, J.W. Comparative analysis of the costs of institutional and community settings. In J.W. Conroy and V.J. Bradley (Eds.), The Pennhurst longitudinal study: A report of five years of research and analysis. Philadelphia, PA: Temple University Developmental Disabilities Center. Boston, MA: Human Services Research Institute, 1985.

Beckman-Bell, P. Parent perspectives. In J. Paul (Ed.), Understanding and working with parents of children with special needs. New York: Holt Rinehart, and Winston, 1981.

Black, M.M., Smull, M.W., Crites, L.S. & Sachs, M.L. Mentally retarded adults and their families: A model of stress and urgency. Baltimore, MD: University of Maryland School of Medicine, 1985.

Boggs, E.M. & Henny, R.L. A numerical and functional description of the developmentally disabled population in the United States by major life activities as defined in the Developmental Disabilities Assistance and Bill of Rights of Act as Amended in P.L. 95-602. Philadelphia, PA: EMC Institute, 1979.

Bradley, V.J. Deinstitutionalization of developmentally disabled persons. Baltimore, MD: University Park Press, 1978.

Bradley, V.J. & Clarke, G. Paper victories and hard realities: The implementation of the legal and constitutional rights of the mentally disabled. Washington, DC: Health Policy Center, Georgetown University, 1976.

Brown, P., Johnson, C. & Vernier, P. (Eds.). Income support: Conceptual and policy issues. College Park, MD: University of Maryland, Rowman and Littlefield, 1983.

Browning, R., Rhoades, C. & Crosson, A. Advancing your citizenship: Essays on consumer involvement of the handicapped. Eugene, OR: Rehabilitation Research and Training Center in Mental Retardation, 1980.

Browning, P., Thorin, E., & Rhoades, C. A national profile of self help/self advocacy groups of people with mental retardation. Mental Retardation, 1984, 22, 226-230.

Bruininks, R.H. The needs of families. In R.H. Bruininks & G.C. Krantz, (Eds.) Family care of developmentally disabled members: Conference proceedings. Minneapolis, MN: University of Minnesota, 1979.

Close, D.W. Community living for severely and profoundly retarded adults: A group home study. Education and Training of the Mentally Retarded, 1977, 12, 256-262.

Close, D.W., Irvin, L.K., Taylor, V.E. & Agosta, J.M. Community living skills instruction for mildly retarded persons. Exceptional Children Quarterly, 1981, 2(1), 75-85.

Conroy, J.W. & Bradley, V.J. The Pennhurst longitudinal study: A report of five years of research and analysis. Philadelphia, PA: Temple University Developmental Disabilities Center, Boston, MA: Human Services Research Institute, 1985.

Crnic, K.A., Friedrich, W.N. & Greenberg, M.T. Adaptation of families with mentally retarded children: A model of stress, coping, and family ecology. American Journal of Mental Deficiency, 1983, 88, 125-138.

Cronbach, L. & Furby, L. How should we measure "change" -- or should we? Psychological Bulletin, 1970, 74, 68-80.

Demos, J. Family home care: Historical notes and reflections. In R. Perlman (Ed.), Family home care: Critical issues for services and policies. New York: The Haworth Press, 1983.

Dywbad, G. The mentally retarded child under five. Arlington, TX: Association for Retarded Citizens, 1966.

Engleman, S. & Carnine, D. Theory of instruction: Principles and application. New York, NY: Irvington Publishers, 1982.

English, R.W. & Olson, K.K. Parenting Handicapped children: Their earliest experiences. The Journal for Special Education, 1978 15(1), 10-17 and 15(2), 169-186.

Evans, I.M. & Meyer, L.H. An educative approach to behavior problems. Baltimore, MD: Paul Brookes Publishing, Co., 1984.

Fortier, L.M. & Wanlass, R.L. Family crisis following the diagnosis of a handicapped child. Family Relations, 1984, 33(1), 13-24.

Gliedman, J. & Roth, W. *The unexpected minority: Handicapped children in America* (Summary). New York, NY: Harcourt, Brace and Javanovich, 1980.

Gottleib, J. Public, peer and professional attitudes toward mentally retarded persons. In M. Begab & S. Richardson (Eds.), *The mentally retarded and society: A social science perspective*. Baltimore, MD: University Park Press,. 1975.

Hall, R.V. & Hall, M.C. *How to teach series* (16 pamphlets). Austin, TX: Pro-Ed, 1980.

Halpern, R. Lack of effects for home-based early intervention?: Some possible explanations. *American Journal of Orthopsychiatry*, 1984, *54*(1), 33-42.

Hauber, F.A., Bruininks, R.H., Hill, B.K., Lakin, K.C. & White, C.C. *National census of residential facilities: Fiscal Year 1982*. Minneapolis: University of Minnesota, Department of Educational Psychology, 1982.

Herman, S.E. *Family support services: Reports on meta-evaluation study*. Lansing, MI: Michigan Department of Mental Health, 1983.

Hill, J.W., Seyfarth, J.P., Orelove, F., Wehman, P. & Banks, P.D. *Parent/guardian attitudes toward the working conditions of their mentally retarded children*. Richmond, VA: Rehabilitation Research and Training Center in Mental Retardation at Virginia Commonwealth University, 1985.

Konanc, J.T. & Warren, N.J. Graduation: Transitional crisis for mildly developmentally disabled adolescents and their families. *Family Relations*, 1984, *33*(1), 135-142.

Kozak, A.E. & Marvin, R.S. Differences, difficulties, and adaptation: Stress and social networks in families with a handicapped child. *Family Relations*, 1984, *33*(1), 67-78.

Lakin, C.K., Bruininks, R.H., Doth, D., Hill, B. & Hauber, F. *Sourcebook on long term care for developmentally disabled people*. Minneapolis, MN: University of Minnesota, Department of Psychology, 1982.

Lonsdale, G. Family life with a handicapped child: The parents speak. *Child Care, Health and Development*, 1978, *4*, (2), 99-120.

MacEachron, A.E. & Krauss, M.W. A national survey of handicapped children receiving public social services: Prevalance rates and service patterns in 1977. *Children and Youth and Services Review*, 1983, *5*, 117-134.

McAndrew, I. Children with a handicap and their families. Child: Care, Health and Development, 1976, 2, 213-237.

Mink, I.T., Meyers, C.E. & Nihara, K. Taxonomy of familiy styles: II. Homes with slow children. American Journal of Mental Deficiency, 1984, 89, 111-123.

Moore, J.A., Hamerlynck, L.A., Barsh, E.T., Spieker, S. & Jones, R. Extending family resources (2nd Ed.). Seattle, WA: Children Clinic and Preschool, 1982.

Moroney, R.M. Mental disability: The role of family. In J.J. Bevilacqua (Ed.), Changing government policies for the mentally disabled. Cambridge, MA: Ballinger Publishing Company, 1981.

Moroney, R.M. Families, care of the handicapped, and public policy. In R. Perlman (Ed.), Family home care: Critical issues for services and policies. New York: The Haworth Press, 1983.

Nihira, K., Meyers, C.E. & Mink, I.T. Reciprocal relationship between home environment and development of TMR adolescents. American Journal of Mental Deficiency, 1983, 88, 139-149.

Nijre, B. (1969). The principle of normalization and its human management implications. In R. Kugel & W. Wolfensberger (Eds.), Changing patterns in residential services, for the mentally retarded. Washington, DC: Government Printing Office, 255-287, 1981.

Perlman, R. (Ed.) Family home care: Critical issues for services and policies. New York, NY: The Haworth Press, 1983.

Rosenau, N. Final evaluation of family support program. Macomb-Oakland, MI: Macomb County Community Mental Health and Macomb-Oakland Regional Center, 1983.

Schroeder, S.R. & Henes, C. Assessment of progress of institutionalized and deinstitutionalized retarded adults: A matched-control comparison. Mental Retardation, 1978, 16, 147-148.

Skarnulis, E. Less restrictive alternatives in residential services. AAESPH Review, 1976 1(3), 40-84.

Snell, M.E. & Beckman-Brindley, S. Family involvement in intervention with children having severe handicaps. TASH, 1984, 9, 213-230.

Sokol-Kessler, L., Conroy, J., Feinstein, C., Lemanowicz, J., & McGurrin, M. Development progress in institutional and community settings. TASH, 1983, 8, 43-48.

Suelzle, M. & Keenan, V. Changes in family support networks over the life cycle of mentally retarded persons. American Journal of Mental Deficiency, 1981, 86, 267-274.

Tausig, M. Factors in family placement decision-making for disabled individuals. Albany, NY: Program Research Unit Office of Mental Retardation and Developmental Disabilities, 1983.

Tausig, M. Factors in family decision-making about placement for developmentally disabled individuals. American Journal of Mental Deficiency, 1985, 89, 352-361.

Turnbull, H.R., Brotherson, M.J. & Summers, J.A. The impact of deinstitutionalization on families: A family systems approach. In R.H. Bruininks and K.C. Lakin (Eds.), Living and learning in the least restrictive environment. Baltimore, MD: Paul Brookes Co., 1985.

Weiss, H. Issues in the evaluation of family support and education programs. Family Resource Coalition Report, 1983, 2(4), 10-11.

Wikler, L. Chronic stress of families of mentally retarded children. Family Relations, 1981, 30, 281-288

Zimmerman, S.L. The mental retardation family subsidy program: Its effects on families with a mentally handicapped child. Family Relations, 1984, 33(1), 105-118.

APPENDIX TWO:

INTERVIEW GUIDE USED DURING SITE VISITS TO SIX STATES

TOPIC INTERVIEW GUIDE

I. INTRODUCTION TO THE INTERVIEW

The Human Services Research Institute (HSRI) is assisting the Commonwealth of Virginia to design a support or subsidy program for families with developmentally disabled members. There are three major components to the project. To begin, HSRI surveyed the literature pertaining to family support and conducted a national survey of existing family support programs. Second, we are visiting six states with family support programs to interview several key informants. This interview is part of that activity. Finally, we will be conducting a parent survey and key informant interviews in Virginia to learn more about the needs and preferences of Virginians.

We appreciate your agreeing to participate in this project. As you know, developing a family support project is not an easy task and Virginians will need to make several difficult choices in the coming months. Hopefully, the information we collect from these interviews will ease the way.

The interview will take about an hour. To help make the process easier to follow, we have divided our questions into six categories including:

- Historical and Present Dynamics regarding your family support program;
- Administrative Issues;
- Family Empowerment;
- Evaluation of the Program;
- Future Directions;
- Advice to Virginians.

Please take time to consider each question and answer as accurately as you can. We truly are interested in your experiences and impressions concerning family support. Your responses will be held in strictest confidence and because we are aggregating collected information no one will be able to associate your name with any responses. So, please be candid.

STATE ______________

II. INTERVIEW PROTOCOL

A. Historical and Present Dynamics

1. Overall, would you characterize the initial impetus for the program as stemming from (-- Can you generalize . . .)

___ mostly consumer organizations/parents (grassroots)
___ mostly government officials
___ mostly service agencies
___ combination (note: ______________________________).
___ other (note who: ______________________________).
___ don't know

a. If grassroots, how were key decisionmakers (e.g., legislators, state officials) in government convinced of the need for a family support program?

b. If government officials, did consumers/parents eventually become excited about having a family support program?

___ Yes ___ No ___ Don't know

If yes: how did this occur?
If no: has this condition hurt the program's effectiveness??

c. Overall, how was a coalition built to muster support for the family support program?

2. About how long did it take from the time the family support program was initially discussed as a worthwhile endeavor until the program was:

proposed to the legislature __________ months
passed by the legislature __________ months
implemented __________ months

3. What were the major barriers that had to be overcome to have a family support program? (Discuss at least the following areas):

- attitudinal barriers
- possible conflict among parents
- possible resistance from existing service providers
- economic barriers -- cost effectiveness
- political barriers

4. a. Initially, what level of funding was requested?: $__________________. (Year: ____)

b. What was finally allocated?: $__________________. (Year: ____)

c. If a & b levels differ, ask why?

5. a. What groups most supported the family support program? (List groups or noteworthy individuals -- and indicate why).

b. What were their key arguments?

c. Did these groups actively work together? (If yes, ask how).

___ Yes ___ No ___ Don't know

6. a. What groups most opposed the family support program? (List groups or noteworthy individuals -- and indicate why).

b. What were their key arguments?

c. Did these groups actively work together? (If yes, ask how).

___ Yes ___ No ___ Don't know

7. Were there any key actors that remained neutral? (If yes, ask who and why)

8. a. Have there been any significant changes in the sources of support or opposition since the program's inception?

___ Yes ___ No ___ Don't know

b. If yes, please explain:

B. Administrative Issues

- Program Design

1. Family Support Programs around the country are generally designed in three ways: cash, support service or both. Your state has a ________________ program. Why was it designed this way? (I.e., were other ways considered and rejected -- why?)

2. a. What are the goal(s) of the program?

___ deinstitutionalization
___ avoid institutionalization
___ enhance parent's capacity
___ other (note: ______________________________)

b. Are any of these goals emphasized more than others? If yes, which ones and why?

___ Yes ___ No ___ Don't know

3. To what extent is the program designed to take into account the changes that occur over time within the developmentally disabled individual and/or family?

4. How were decisions made regarding:

a. services eligiblity:

- What were the primary issues discussed?

- What if any, are the implications/problems with what was decided (e.g., equity disability vs. income eligibility).

b. Amount or variety of service provided?

- Do you feel that the variety of services is sufficient? Discuss.

___ Yes ___ No ___ Don't know

- Do you feel that the amount of services available is sufficient? Discuss.

___ Yes ___ No ___ Don't know

- Do you feel that there are any major problems with how services are provided? If yes, discuss.

  ___ Yes ___ No ___ Don't know

- Financial

5.a. What are the sources of funds for the program and their relative contributions?

___ federal (specific sources) ___%
___ state ___%
___ county ___%
___ state DD council ___%
___ others (list ______________) ___%
Totals = 100%

If federal was checked, ask what specific sources

b. Has the state been granted a medicaid waiver?

___ Yes ___ No ___ Don't know

If yes

- Were the income eligiblity criteria waived?

  ___ Yes ___ No ___ Don't know

- Can the state use waiver dollars to support families?

  ___ Yes ___ No __ Don't know

  -- If yes, how many waiver dollars used in the past year? $________________________

- Do parents contribute money that the state uses to match for federal funds?

  ___ Yes ___ No ___ Don't know

6. Is there a fee for service? If yes, how does it work? (e.g., Sliding scale? What % do parents pay?)

   ___ Yes ___ No ___ Don't know

7. For subsidy states only (Michigan, Rhode Island, Florida, Ohio).

   a. Have parents lost any benefits (e.g., Medicaid, SSI) due to the subsidy? (i.e., are subsidy dollars considered part of income?) If yes, discuss

      ___ Yes ___ No ___ Don't know

   b. Is the money taxable (federal/state/local)? If yes, discuss

      ___ Yes ___ No ___ Don't know

8. Were developmental disabilities service dollars turned back to the state general fund last fiscal year?

   ___ Yes ___ No ___ Don't know

   If yes, ask how much? $_______________

If yes, ask how many of these dollars were earmarked for family support? $____________

9. Have there been any initiatives aimed at utilizing the private sector to complement services offered by the program? (e.g., corporate day care, in health insurance, for housing adaptations) If yes, discuss.

___ Yes ___ No ___ Don't know

- **Service Provision**

10. How is the program coordinated with other services for developmentally disabled individuals and their families? (e.g., school, hospitals)

___ Yes ___ No ___ Don't know

11. As the program has been implemented, have there been any major issues/problems with such coordination?

___ Yes ___ No ___ Don't know

If yes, what are they and how are they being addressed/rectified?

12. a. What type of quality control or monitoring is being done?

b. Is it working effectively?

c. Any suggestions for improvement?

13. Has there been a woodwork effect (more people applying for service than anticipated)? Discuss

___ Yes ___ No ___ Don't know

14. Is there a waiting list?

___ Yes ___ No ___ Don't know

If yes,

a. how many on the list? __________

b. What plans are being made to deal with it?

15. Has there been any discussion of re-designing the program to "cross-cut" other disadvantaged populations -- maybe merging with other similar services in the state (e.g., elderly, physically disabled, emotionally disturbed)?

___ Yes ___ No ___ Don't know

C. Locus of Control

1. When the program was in the planning stages to what extent were parents involved?

2. How do consumers/parents have input on the planning and delivery of services?

-- on individual level (their own service plan) is there an appeal process? describe: (-- who pays for appeal if there are financial changes?)

-- on system level (program as whole)

Both formally and informally

Are you pleased with these mechanisms? What suggestions if any would you make?

D. Evaluation

(Get copy of formal evaluation if one was done)

1. What are your general impressions of the program's

-- strengths

-- weaknesses

2. What would you suggest be changed or improved in the program?

3. a. To what degree has the program increased the capacity of parents to care for their disabled child/adult at home?

b. To prevent institutionalization?

4. Has there been a consumer statisfaction study done?

___ Yes ___ No ___ Don't know

If not, why not?

If no, what do you think parents like most/least about the program?

-- most

-- least

E. Future Directions

1. What do you forsee as the future of this program? (i.e., growth, stability, service/ administrative changes)

2. If you could give Virginia advice, what would you advise them to do/not do?

APPENDIX THREE:

DESCRIPTIONS OF FAMILY SUPPORT PROGRAMS IN SIX STATES

FLORIDA

NAME OF PROGRAM:

There are two family support programs in Florida -- the Independent Family Living Program (IFLP), and the Family Placement Program (FFP), which is a small program operating within the auspices of the IFLP

DATE INITIATED:

The Independent Family Living Program was initiated in 1973, while Family Placement Program was begun in 1978.

ADMINISTERING AGENCY:

Department of Health and Rehabilitative Services; Office of the Developemental Services Program

HISTORICAL BACKGROUND:

Florida's family support program has been in place approximately 12 years and provides a variety of services to clients living in their homes and to their families. Most families served by the program receive inkind supportive services, while some families are served through a newer cash voucher system.

The initial family support program (IFLP), begun in 1973, was developed as a result of two basic factors. First, Florida was among the first states to promote community services over institutional services. The last institution in Florida was established in 1967, and the pressure for initiating community services was strong by 1972-1973. Institutional populations declined from 6045 in 1971 to 2324 by 1984. Conversely, those served in community residences grew from 371 in 1971 to 5524 by 1984. Concurrent with this trend was a growing recognition among state policymakers that de-emphasis of institutional services had to be complemented by the initiation of support services for clients living at home with their families.

The second factor pertains to the pressure exerted in the state legislature by advocacy groups, especially the Florida Association for Retarded Citizens (FARC). In great part due to the efforts of the FARC, a Bill of Rights Act for persons with developmental disabilities was passed by the state legislature in 1975 and the Community Services Act was passed in 1977. This latter act created the Family Placement Program as a companion program of IFLP.

In essence, the Florida family support program reflects a commitment by the state legislature to community based services and a recognition that family-based care is an essential part of the community services structure. Such legislative support, however, was earned on the basis of effective lobbying by advocates and the willingness of state officials to puruse a communitization policy.

PROGRAM PURPOSES:

The overall purpose of the Florida family support programs are to enable persons with developmental disabilities to remain in a family setting, avoiding or reducing the necessity for institutional placement. In specific the programs aim to: 1) make it possible for persons in instititutions to return to their natural families, 2) deter out-of-home placement, 3) enhance the caregiving capacity of families, and 4) provide the person with disabilities who lives at home with suitable services.

PROGRAM TYPE:

The IFLP is a supportive services program in which the state purchases a variety of services for persons residing in their family home.

In contrast, the FPP is a cash voucher system where parents are reimbursed for services they purchase. These services must be deemed as necessary for the habilitation of the client and unavailable through the auspices of any state agency.

ELIGIBILITY CRITERIA:

To be eligible for family support services, the disabled family member must have a developmental disability, be a client of the Developmental Services Program, and be at risk of an out of home placement.

EXPENSE OR SERVICE LIMIT:

There is no limit on the amount of resources that could be expended per family. However, given the limitations of the overall budget, restrictions are applied based on the judgment of each client's habilitation team and the budgets of programs in each of Florida's eleven health care districts.

NUMBER SERVED:

The IFLP served 8,229 persons during FY 1983-1984.
The FPP served 210 persons during FY 1983-1984.

PERMISSIBLE SERVICES:

Under the auspices of the IFLP, a variety of services are provided to clients living at home including case-management, developmental training, transportation, occupational therapy, physical therapy, speech therapy, counseling, and adaptive equipment. In addition, a parent training program was established in 1977 for parents of children with disabilities aged 0-4 years.

As noted earlier, the FPP provides parents with reimbursement for services that cannot be obtained under the auspices of another state agency. These expenses could include basic residential costs, certain medical/dental care, sitter services, day care, transportation, special equipment or assistive devices, rennovations to the home, climate control equipment, special diets, special clothing, or any other unusual expenses related to the client's disability.

AMOUNT AND SOURCES OF APPROPRIATIONS:

Florida has been granted a Title XIX community based waiver. Part of the waiver program can be used to promote family care. Thus, the state's family support initiatives are funded by a mix of state funds (about 52%), waiver dollars (about 21%), and other sources (about 26%).

Expenditures for the IFLP totaled $21.4 million during FY 1984-1985. Of this total, $1.2 million was allotted to the FPP.

STRENGTHS:

Florida's family support program is nearly 12 years old and no doubt has had a positive impact on numerous persons. Its greatest strengths, however, appear to rest in three areas. First, the program continues to enjoy widespread support from state officials and advocacy groups. Certainly the influence exerted by FARC on the legislautre over the years suggests that the program will continue to gain strength.

Second, since 1977 Florida has operated a progressive cash assistance program for some families (through the FPP). This program is based in a recognition that the state presently does not not supply the full array of needed family support services. Thus, this innovative service is structured to fill gaps in services and to be fully responsive to individual family needs.

Third, the state has been aggressive in ensuring that clients enrolled in the IFLP have individualized

Third, Florida's family support initiatives seem to focus almost exclusively on the person with disabilities, the "client." Though the family is recognized as the caregiver, few services are directed toward strengthening its capacity to provide care. Note that: 1) services provided through the IFLP are for the client, 2) parent training is available only to parents of very young children, and 3) the more premissive FPP reaches only 210 families. Other states are increasingly recognizing the importance of services directed toward family members to improve family dynamics and its understanding of the problem, and to enhance its caregiving capacity. Examples of such services include counseling or physical therapy for family members. Florida's program could be embellished if it were to permit these and other services for family members.

Finally, there are no recent systematic evaluations of Florida's family support programs. Such evaluation could be used to increase the programs' efficiency and effectiveness.

habilitative plans (IHP). Ideally, the family is encouraged to participate in the IHP process so that the client's needs are met and so that the service plan can enhance the family's efforts. This system has two positive effects. First, it makes the IFLP accountable to service consumers and funders. Through systematic review of IHPs, the services rendered to individual families can be evaluated for their appropriateness and effectiveness. Second, it encourages family involvement in the entire service delivery process. Though state officials suggested that some families elect not to participate in developing the IHP, leaving professionals to design the plan without family input, they emphasize that the opportunity for family participation is present.

WEAKNESSES:

On the negative side there are four issues. First, the programs are not funded at a sufficient level. Though there is significant support for the programs among state officials and advocates, out-of-home services still receive the lion's share of the funds. An appropriation of $21.4 million annually for the programs may seem generous, but Florida annually spends $150 million on clients living in alternative residences. Given that a minority of persons with developmental disabilities reside away from their families, this funding pattern appears unbalanced to many.

This shortcoming manifests itself in a variety of administrative practices. Consider how services are distributed to families. Though the FPP is an innovative initiative that is highly regarded, it only serves 210 families. Similarly, parent training is viewed as key to promoting effective family care, but is restricted to parents with children aged 0-4 years. In addition, funding shortages have inhibited state officials and advocacy groups from publicizing the availability of family support services for fear of stimulating a demand for services that could not be met. Thus, it seems likely that the present family support initiative does not reach all those families who would qualify for services, if they were to apply.

A second problem concerns the FPP. This program utlizies a reimbursement strategy for providing families with cash assistance. This tact was chosen primarily because it is easier for state officials to direct and track what is purchased. However, it would seem that if parents received cash prior to purchasing needed services, the strain on family resources would be relieved more effectively.

MICHIGAN

NAME OF PROGRAM:

There are two family-centered programs in Michigan, the family support subsidy, and family support services.

DATE INITIATED:

The Family Support Subsidy Act was passed on December 15, 1983, and became operative on July 1, 1984. Family support services were initiated as part of a pilot project in 1978 and were expanded in 1984 to the entire state.

ADMINISTERING AGENCY:

The Family Support Subsidy Act is administered by the Michigan Department of Mental Health and the state's 55 community mental health boards. Applications for the subsidy are made to the boards that verify the information provided. The board has the option to contract with the state to write the checks. At the time of the site visit, only two boards had not entered into such contracts. It was anticipated that, over time, more boards would chose to administer the payment as well as the eligibility determination. The state also provides some verification.

With respect to family support services, funds are made available through requests for proposals to the community mental health boards. The boards in turn primarilly contract out for services although some provide services directly.

HISTORICAL BACKGROUND:

The history of the family support effort in Michigan began in 1978 when a $100,000 state grant for family support services was made available from the legislature to a community mental health board in the Lansing Area. Instead of providing services through the community mental health center in the conventional fashion, the implementation of the grant was directed by a group of parents of children with severe disbilities. The grant was used to start a respite program and funds were made available in equal amounts in a "bank" for families enrolled in the program.

An additional $500,000 was appropriated by the legislature to establish pilots at three other sites. At one of the sites, Macomb Oakland, a cash subsidy was tried. The parents that started the original pilot in the Lansing area formed the nucleus of a parent task force that began to work closely with Representative Debbie Stabenow in the Michigan Legislature.

As early as 1980, the notion of a cash subsidy for families with severely handicapped children was discussed. The first application of the idea came with the passage of a cash subsidy for parents who adopted children with handicaps. In an effort to gain support for a similar subsidy to natural parents, Representative Stabenow and members of the task force as well as representatives of the Developmental Disabilities Council began to mount a multi-faceted campaign. The Council sponsored a variety of activities that raised the consciousness of parents and others regarding the needs of families including workshops and parent training sessions. The task force members reached out to parents around the state and enlisted them in the effort to pass legislation.

When the legislation was finally introduced, much of the political organizing had been done. There were, however, some objections to be overcome. The first came from some advocates and professionals who felt that the subsidy might take funds away from direct services. This point was particularly relevant in Michigan given the difficult economic situation that the state faced in the early 1980s. Another hestitation came from representatives of the state Department of Education who were concerned about the use of special education categories as the basis for eligibility for the subsidy. Also, some professionals were concerned about giving money to family members without the involvement of professionals to oversee the use of the funds. Finally, some legislators felt that a tax credit was a more appropriate way of supporting families than through a direct grant.

These arguments were ultimately overcome by a highly organized lobbying and information campaign. Family members in every legislative district were contacted and sent letters of support to their representatives. Family members testified about their personal experiences before committees and brought their children to hearings. The results of the evaluation of the pilot projects were also useful since they showed that support services had a positive effect on the families served. Further in the one pilot that employed cash subsidies, the study findings indicated that placement was averted for ten disabled children and another three were removed from placement and brought home. Supporters of the bill also argued that if foster and adoptive parents were receiving subsidies to care for disabled children, then natural families should be eligible for the same benefits.

The author of the bill presented fiscal analyses comparing the costs of subsidy with the costs of out-of-home and institutional placements. She also argued that though the state had made a real commitment to deinstitutionalization and the development of community alternatives, natural families who maintained their children at home had gotten short shrift.

The family subsidy legislation passed on December 15, 1983 and became operative on July 1, 1984.

With respect to family support services, the legislature appropriated approximately $4 million for fiscal year 1984-1985 for a range of services to be delivered by local community mental health boards statewide.

PROGRAM PURPOSES:

The major purposes of the family subsidy program in Michigar are: to prevent and/or delay the out-of-home placement of severely disabled children; to improve the quality of life for families; to make it possible to bring children home from institutions and other residential facilities; to provide funding for the special needs of disabled children; and to recognize the contributions made by natural families to the care of their disabled members.

PROGRAM TYPE:

Michigan has two types of family support activities -- a cash subsidy program, and family support services provided through the local community mental health boards.

ELIGIBILITY CRITERIA:

In order to be eligible for the family subsidy program, a family must: 1) have a taxable income of $60,000 or less (based on Michigan tax requirements); 2) have a child under 18 years old, living at home who has been assessed by the school district's multidisciplinary team to be severely mentally impaired, severely multiply impaired; or autistically impaired; 3) submit a tax return for the most recent tax year; 4) reapply every year to ensure continuing eligibility; and 5) fill out a form once a year regarding how funds were spent. Families not eligible include those whose children are in private schools or who have not as yet been enrolled in special education.

Support services through the community mental health boards are available to families of children of all ages. There is no limit on family income since services are available on a sliding scale.

EXPENSE OR SERVICE LIMIT:

Every family that is eligible for a subsidy receives $225.00 per month. The amount is based on the amount of Supplemental Security Income that an adult living in the home of another would be receiving. With respect to respite services, each eligible family is given a specified amount per quarter to use as they wish. More funding can be requested in unusual circumstances.

NUMBER SERVED:

When the family subsidy legislation was proposed, it was estimated that approximately 2,000 families in the state would be eligible. At the time of the site visit, 1900 families had already applied and it appeared that the 2,000 figure would be surpassed by at least another 200 or 300 families. There were already discussions about the need for a supplemental appropriation.

Figures were not available on the numbers of persons receiving family support services through the community mental health boards.

PERMISSIBLE SERVICES:

Families can use their cash subsidy for anything they wish.

Services that can be provided through community mental health boards include: respite and sitter services, case management, parent training and education, parent support groups, financial assistance, assessment and evaluation, therapeutic intervention, crisis intervention, homemakers, home health care, and personal care.

AMOUNT AND SOURCES OF APPROPRIATIONS:

For the first six months of the family subsidy program, July - December 1984, $2 million was appropriated. The full fiscal year funding will be $4.5 million, although it is estimated that another $1 million may be required to meet the unanticipated demand.

Approximately $4 million has been appropriated for family support services to be provided at the local level.

STRENGTHS OF THE PROGRAM:

The major strength of the family subsidy program is its simplicity. There are no complicated income requirements, the amount is pegged to SSI for an adult living in the home of another, and the disability determination is made in tandem with the special education evaluation.

Demand over time should also be predictable since the number of children falling into the three disability categories is a finite number, and trends over time can also be easily determined.

Another strength is the evaluation that is being done of the impact of the family subsidy program in Michigan. Very few states have done systematic evaluations of their family support programs. This study should be enormously valuable since it involves a pre- and post- subsidy assessment.

The manner in which the subsidy is administered minimizes bureaucracy and maximizes the dignity of the individual family. It also minimizes the cost. Given the variation in the types of problems encountered by families, the subsidy also gives parents the flexibility to tailor their purchases to the specific needs of their child.

Further, the subsidy tends to counteract the overwhelming fiscal incentives that favor out-of-home placement, and it may contribute to bringing some children home. It also, according to parents who participated in the earlier evaluation, alleviates family stress and improves the quality of life for all family members.

Finally, the process of designing and implementing the subsidy brought parents and administrators together into a close and collaborative arrangement.

WEAKNESSES:

The current family subsidy program does not include non-retarded physically handicapped children, or severely mentally ill children. Discussions were taking place at the time of the site visit regarding the fiscal and political implications of including these children.

There are still some issues to work out between the Department of Mental Health and the Department of Education. Education officials are still concerned that tying the eligibility for the subsidy to special education categories may in some way compromise the integrity of that process. One suggestion was to have the Department of Mental Health handle all of the appeals for a re-evaluation when the determination of the multi-disciplinary team is questionned.

With respect to support services, there are still problems securing services such as respite care and transportation especially in rural areas. Further, the quality of services varies from local area to local area. Finally, not all community mental health boards have applied for funding for family support services.

not have significant deficits in two or more areas of adaptive behavior are not eligible.

EXPENSE OR SERVICE LIMIT:

According to statute, there is a $2,500 limit per family per year. In reality, 96% of all eligible families receive less than $600 worth of services. Families share the cost of services according to their income and the number of dependents (sliding scale).

NUMBERS SERVED:

Data is not yet available since statewide implementation of the program only began July 1, 1984.

PERMISSIBLE SERVICES:

Services allowed under the program include in-home or out-of-home respite care; counseling, training and education for family members; special diets; purchase or lease of special equipment; and home modifications.

AMOUNT AND SOURCE OF APPROPRIATIONS:

For fiscal year 1985, the legislature appropriated $2.0 million in state general funds.

STRENGTHS:

Although Ohio's Family Resources program in less than a year old, several major strengths are observable. First, parents and advocates have carefully constructed a framework for service delivery that clearly incorporates families into the planning and evaluation of services. Each county MR/DD board is required to receive and document imput from parents regarding their need for service. Then the Board must hold a public hearing on its preliminary plan and consider all testimony received at the hearing in revising the plan. Furthermore, the MR/DD Board must annually evaluate its FRS program using data collected from families and consumers, as well as other sources. There is also an appeal process for families who were denied FRS services.

Second, of the five services that are available, respite care and family counseling and training directly benefit the family. Adaptive equipment,home modification and special diets benefit the disabled person. State support for such a service array reduces the economic burden on the family of caring for a disabled member.

OHIO

NAME OF PROGRAM:

Family Resources Services (FRS)

DATE INITIATIED:

The Family Resources Services began recently in 1983.

ADMINISTERING AGENCY:

The program is administered by the Department of Mental Retardation and Developmental Disabilities, and implemented at the local level by County Mental Retardation and Developmental Disabilities Boards.

HISTORICAL BACKGROUND:

In 1980, the Ohio Developmental Disabilities Planning Council funded a research project to assess the demand for respite care statewide. It also funded several respite care demonstration projects. In 1982 an informal group of parents, professionals, state officials and legislative aides, drafted family resource legislation. The "respite coalition," consisting of respite demonstration projects, joined forces with a larger legislative coalition comprised of the Ohio Association for Retarded Citizens, Developmental Disabilities Council, Private Residential Facilities Association, Professional Association for the Retarded, and Ohio Superintendents of County Boards of Mental Retardation and Developmental Disabilities, to pursue family support legislation, which passed in 1983.

PROGRAM PURPOSE:

The FRS program provides services to families that "promote self-sufficiency and normalization, prevent or reduce inappropriate institutional care, and further the unity of the family by enabling the family to meet the special needs of the mentally retarded or developmentally disabled persons." (Ohio Code, Section 5726.11)

PROGRAM TYPE:

Supportive Services

ELIGIBILITY CRITERIA:

The family must contain an individual who: a) has mental retardation or other substantial developmental disabilty; b) lives at home; and c) is in need of habilitation services. Persons who have mild mental retardation or do

WEAKNESSES:

On the negative side, Ohio's FRS program is significantly underfunded. If all potentially eligible families requested their allowable $2,500 worth of services, the annual budget would have to be significantly higher. In addition, the eligibility requirements are restricted to individuals with servere handicaps, and therefore prevent many families from receiving services. For instance, a family requesting counseling to cope with a mildly retarded, emotionally disturbed family member would be denied. Similarly, a family requesting home modification or a wheelchair for a physically disabled, cerebral palsied member would be denied.

PENNSYLVANIA

NAME OF PROGRAM:

Family Resource Services (FRS)

DATE INITIATED:

Pennsylvania's program for families, which began in 1972, is the oldest in the country.

ADMINISTERING AGENCY:

The program is directed at the state level by the Office of Mental Retardation in the Department of Public Welfare, and at the local level by county boards of mental health and mental retardation.

HISTORICAL BACKGROUND:

The program began at a time when Pennsylvania was developing a variety of community services and reducing the size of its state schools. State program staff, many of whom had been recruited from the ENCOR program in Nebraska, also recognized the importance of the family as the primary unit responsible for caring for a mentally retarded person. The opportunity to implement such a program came in 1972 when a $700,000 suplus was available in the residential services budget. Using this money, the Director of Community Services funded the first family resource services.

PROGRAM PURPOSES:

The purpose of the FRS program is to make the necessary support services available to enable a family to maintain their mentally retarded family member at home. It also makes support services available to mentally retarded persons living independently. The goal of the program is to reduce the need for institutionalization and to promote deinstitutionalization.

PROGRAM TYPE:

Support services

ELIGIBILITY CRITERIA:

The following groups are eligible for family resource services:

1) Persons with mental retardation who live at home with their natural or adoptive families, foster families, relatives or legal guardians;

2) Persons with mental retardation who live independently in the community;

3) Natural or adoptive families, foster families, relatives or legal guardians who are maintaining a person with mental retardation at home.

EXPENSE OR SERVICE LIMITS:

Services are provided based on individual needs, available funding, and the ability of the county to provide the services. Family aide service has a limit of four 24 hour sessions per family per month. There is no parent liability for this service. In 1979/80, the average cost for family resource services per family per year was $1,734.

NUMBER SERVED:

During fiscal year 1983-84, 13,000 persons were served.

PERMISSIBLE SERVICES:

The following services can be provided directly or subcontracted by the local county mental health and mental retardation programs: respite care; family aide (sitter/companion services); homemakers; recreation; in-home therapy (physical therapy, occupational therapy, speech and language therapy); mobility training; family training innovative services; adaptive appliances; home repairs (minor); hearing aide evaluation; sign language training; behavioral programming; and special diets.

AMOUNT AND SOURCE OF APPROPRIATIONS:

For fiscal year 1983-84, the total amount spent for family resource services was $3.6 million (90% state, 10% county match).

STRENGTHS:

Pennsylvania's Family Resource Services Program allows a wide range of services to a large number of families and individuals with mental retardation. The program has strong support from the Department of Public Welfare, as evidenced by the fact that the only mental retardation program in 1984 that received a budget increase of $2.5 million. The Pennsylvania Association for Retarded Citizens has also taken a leadership role in training parents to advocate for the Family Resources Program on the local level.

Family Resources is also a popular program among the county mental health and mental retardation programs. In FY 1982/83, categorical funding for family resources was eliminated and the funds were folded into the county base allocation. This move seems to have had a positive effect since 78% of the counties increased funding for family resource services in FY 1983/84.

WEAKNESSES:

Nonetheless, there are several weaknesses in the Family Resources Program. Two of the problems, restrictive eligibility and lack of equity across the state relate directly to the organization of Pennsylvania's mental retardation system. Specifically, eligibility is restricted to people who are mentally retarded, and therefore does not include other developmentally disabled persons with physical disabilities alone. Further, since Pennsylvania's system is county controlled, there is a wide disparity in the amount and nature of family support services delivered across the state. In fact, only 16 out of 43 County Board offered the full range of family support services in fiscal year 1981/82. Furthermore, many interviewees identified a lack of innovation and creativity on the county level regarding the way in which services are provided. Another common complaint was that services are not "demand responsive" to the needs of families, but instead are dictated by county staff.

RHODE ISLAND

NAME OF PROGRAM:

Parent Deinstitutionalization Subsidy Aid Program

DATE INITIATED:

1977

ADMINISTERING AGECNY:

Department of Mental Health, Retardation, and Hospitals; Division of Mental Retardation

HISTORICAL BACKGROUND:

To understand how the Rhode Island Program was initiated, three factors must be understood. First, the state is "small and personal." Several persons emphasize that Rhode Island's small size promotes increased cooperation and communication between key state decisionmakers and various advocates. Second, advocacy groups -- especially the Rhode Island Association for Retarded Citizens (RIARC) -- enjoy a longstanding productive relationship with the state's legislature. The RIARC has been quite active over the years, winning national acclaim in the 1970's for its efforts to promote community services. Moreover, the long term house majority whip has a son with disabilities. Consequently, communitization advocates enjoyed the support of a significant key actor in the legislature for several years. Third, the timing of the program's planning and implementation was opportune. In the 1970's the state was under considerable pressure from advocates and the courts to correct unsatisfactory conditions at state institutions and to begin developing community based service alternatives. The initiation of a family support program was a natural outgrowth of this movement.

These factors worked in tandem to create momentum for initiating a small cash susidy program for parents. At the base of this movement -- and this cannot be overemphasized -- was timely grassroots support for the program. State officials initially were not supportive of the program. Continued pressure from the RIARC and other communitization proponents, however, resulted in the program's creation. Since these early beginnings, the program has gained the full support of state officials and has grown modestly. At present, an early intervention program, funded with Title XIX community waiver dollars, complements the cash subsidy program.

PROGRAM PURPOSES:

Initially, the primary purpose of the Rhode Island family assistance program was to encourage parents to have their son or daughter with disabilities return to the family home from placement in a state institution. Since its inception, however, the program's purposes have been informally expanded to include avoidance of unnecessary out-of-home placement and enhancement of the family's capacity to provide care. In addition, an early intervention program (for children aged 0-3) was begun that complements the parent cash subsidy program, and whose primary purpose is to discourage out-of-home placement.

PROGRAM TYPE:

Combination cash subsidy and supportive services.

ELIGIBILITY CRITERIA:

For the cash subsidy program, the family member with a disability must have mental retardation. Moreover, the member with a disability must meet the admission criteria for the public institution and the family must be having problems the provision of care.

For the early intervention program the family member with a disability must have a developmental disability and be aged 0-3 years.

EXPENSE OR SERVICE LIMIT:

Regarding the subsidy program, families receive case management services and cash payments of not less than $25.00 nor more than $75 per week for the basic care of each child or adult ($1300 - $3900 per year) and $5.00 to $15.00 a week for the training of the child or adult ($260 - $630 per year).

Expense limits pertaining to the early intervention programs are not as concisely stated. Families can receive a variety of free supportive services, while their child with disabilities receives specialized educational services.

NUMBERS SERVED:

Cash Subsidy Program: 65 in FY 1983 with 17 on a waiting list.

Early Intervention Program: 390 in FY 1983.

PERMISSIBLE SERVICES:

The following services are covered by the Rhode Island program: case management, adaptive equipment, medical/dental services, educational/therapeutic services for the person with disabilities, housing modifications, respite care, family training or counseling, and homemaker assistance.

AMOUNT AND SOURCES OF APPROPRIATIONS;

Rhode Island has been granted a Title XIX community based waiver. Part of the waiver program is aimed at promoting family care. Thus, the state's family support initiatives are funded by a mix of state funds (about 60%), federal funds (about 35%), and other private sources (about 5%).

Total expenditures totaled $256,000 for the cash subsidy program in FY 1983 and $670,000 for the early intervention program in FY 1984.

STRENGTHS:

This program's greatest strength rests with the overall sense of accomplishment and satisfaction shared by many of those who are associated with it. This stems in part from the fact that the program was begun due to the efforts of numerous parents and advocates at the grassroots level. Consequently, though state officials are responsible for its administration, advocacy groups (e.g., RIARC) feel a sense of ownership for the program and still exert considerable influence over its substance and direction.

A second strength pertains to the use of a cash subsidy. Though certain free, in-kind services are also available to some parents through the early intervention program, the subsidy allows parents a greater sense of control over the services they may want to purchase (e.g, respite). Moreover, it recognizes the family as a service provider and compensates families for their day-to-day caregiving efforts.

A third strength pertains to the use of a "general service plan" for each family. In meeting periodically with a case manager and various professionals, the family helps set long term goals and short term objectives for itself and for its member with a disability. In this process the family is viewed as a vital component. However, recognizing that not all families are willing or capable of taking the lead at formulating the service plan, the planning team acts to assure that the family makes greatest use of the subsidy it is provided and/or the early intervention services it receives.

WEAKNESSES:

Though the Rhode Island program is based on grassroots support and is progressive in its use of a cash subsidy, it suffers from at least four shortcomings. First, it serves relatively few families. In FY 1983 the number of families receiving a cash subsidy totaled 65 with a waiting list of 17. It is obvious to many of those associated with the program that the number of families qualifying for the subsidy would grow much larger if the program were publicized. Due to insufficient funds, however, the program continues to serve surprisingly few families and is not advertised widely.

Second, the use of Title XIX community waiver dollars, though useful, is not troublefree. Several persons indicated that the waiver has proven difficult to implement as originally envisioned. For instance, not as many persons are being served through the waiver than anticipated, due to conservative interpretations of eligiblity standards. Moreover, satisfactory administrative processes have been difficult to plan and implement.

Third, relatively few services are deemed permissible. Certainly, the program allows or provides several crucial services (e.g., case mangement, respite, etc.). However, families are individual entities and have a wide variety of needs. A preferable design would allow a wide variety of permissible services. Nebraska and Maryland allow as many as 14 services and maintain provisions for permitting purchase of unique services. If additional services were deemed permissible in Rhode Island, families could select services from a comprehensive service menu, resulting in a more effective response to individual family needs..

Finally, there has been no systematic evaluation of the program. The primary benefit of such evaluation would not be to justify ongoing funding for the program. Rather, program evaluations could be undertaken to determine what can be done to improve program efficiency and effectiveness.

WASHINGTON

NAME OF PROGRAM: Home Aid Program

DATE INITIATED: 1975

ADMINISTERING AGENCY:

The Division of Developmental Disabilities (DDD), a division of the Washington Department of Social and Health Services (DSHS), administers the Home Aid Program through six regional offices. DSHS contracts directly with providers for home aid and residential services (as compared with day habilitation services which are administered through the counties under contract with DSHS). Case management is provided through six state regional offices.

HISTORICAL BACKGROUND:

The Home Aid Program is based on family support models that originated in Sweden, and were brought to the Developmental Disabilities Planning Council by parent/advocates who traveled there in 1974. The legislation was passed in 1975 and provided for respite and other support services for families with disabled relatives of all ages.

In order to secure passage of legislation to establish a home aid program, parents around the state were organized into "mother's clubs" which stood ready to contact local legislators. Sympathetic law makers were contacted to introduce the legislation including one who was also the parent of a disabled child. Eventually, the entire disabilities community became involved. Parents initially considered the possibility of including a cash subsidy in the legislation, but could not garner sufficient support. The only real conflict encountered in the campaign for the home aid bill was with family members of disabled persons in institutions who were fearful that care for their relative might somehow be compromised. Parents argued that, rather than costing more, the home aid program would in fact save money since it would keep more disabled children at home with their families and out of institutions or other residential settings.

More recently, the Division of Developmental Disabilities sponsored a comprehensive long term planning project. The number one priority in the plan is family support services funded at increased levels. The proposal outlined in the plan would combine home aid services with two other programs -- program options and the community alternatives program. The latter two programs are discussed subsequently.

PROGRAM PURPOSES:

The goals of the program include: 1) promoting deinstitutionalization, 2) preventing institutionalization, 3) enhancing parents' capacity to maintain their developmentally disabled family member at home, and 4) enhancing the quality of life for the family, 5) creating a normalized environment for the child.

PROGRAM TYPE:

Supportive Services

ELIGIBILITY CRITERIA:

Clients must be severely developmentally disabled as defined by state statute and the Washington Administrative Code. Non mentally retarded severely physically involved persons are eligible. No means test is applied to those under 18 years of age, but clients who are age 18 and over must meet an income eligibility requirement. With respect to equipment or home adaptations, families must first exhaust their own resources before they are eligible.

EXPENSE OR SERVICE LIMITS:

With respect to respite services, state case managers can authorize 216 hours or 27 days a year. This amounts to only two days a month except in emergencies. The average per family is 15 days. Services can only be provided if the case manager approves. Family members must schedule respite services at the beginning of the month in which the service is needed. All respite care providers must 18 years or older, must be approved by the state, and if the service is provided at the provider's home, the home must be licensed. The amount available for a day of respite care is $38.00.

NUMBER SERVED:

Although no state waiting lists are maintained, estimates suggest that service availability does not match service need. Of approximately 6,000 Division of Developmental Disabilities clients living with their families, only about 2100-2200 currently receive Home Aid support.

PERMISSIBLE SERVICES:

Through Home Aid, clients can receive attendant care, behavior management consultation and specialized equipment, in addition to respite care and specialized therapies. Until recently, however, the primary home aid service was out-of-home respite care. Augmentations to the 1985-87 biennium budget for home aid services are targeted on an expansion of such services as parent training, consultation, and attendant care.

AMOUNT AND SOURCE OF APPROPRIATIONS:

A state funded program, Home Aid received approximately $2.5 million in appropriations for the 1982-1984 biennium. The Division of Developmental Disabilities is requesting $3.5 million for the 1985-1987 biennium, although those association with the long range planning process recommended upwards of $6 million for the next two years.

STRENGTHS:

One of the major strengths of the home aid program cited by parent advocates is the fact that home support services can be secured by a family regardless of income. Services are available in most communities and they have helped families to cope better with the demands of a severely handicapped child. Further, respite care providers are screened and certified by the state. Finally, the home aid program potentially encompasses a wide range of home supports that can be used flexibly to meet the unique needs of each family.

WEAKNESSES:

For many of those contacted in the state, the home aid program has become overly bureaucratic and inflexible. Instead of empowering families, some complained that the program is no longer based on the needs of families, but rather on those of the system. Because of the red tape, some noted that it was difficult to recruit providers (occupational therapists, physical therapists, etc.). Delays in reimbursements also contribute to recruitment problems. Finally, there was concern that the quality and availability of services varied from region to region.

NAME OF PROGRAM:

Program Options and Community Alternatives Program (CAP)

DATE INITIATED:

The Program Options program was initiated by the Washington Legislature in April 1983. The application for federal approval of the Community Alternatives Program was filed in mid 1983 with the Health Care Financing Administration.

ADMINISTERING AGENCY:

Program Options is administered through six regional offices of the Division of Developmental Disabilities. A Program Options Coordinator is assigned in each region to oversee program applications, case managers work directly with applicants, and the Regional Administrator reviews and recommends cases to the Assistant Director of Field Services.

The Community Alternatives Program, which is supported through the Community Services Waiver under Title XIX, is also administered by the Division of Developmental Disabilities by delegation from the single state Medicaid agency. Applications and eligibility determinations are made through the Division's regional offices.

HISTORICAL BACKGROUND:

Consistent with the goal of providing more individualized and less restrictive programs for persons with developmental disabilities, Program Options was developed by advocacy groups with the support of the Department of Social and Health Services. Introduction of the legislation coincided with a surplus generated in the Division of Developmental Disabilities budget which made the passage of a new and experimental program more attractive. Program Options allows families to develop their own program alternatives, as the total service package does not cost more than 80% of their relatives' current program (usually residential).

CAP was included in the state's Title XIX waiver application in 1983 and was aimed at families whose relatives were potential candidates for an ICF/MR level of service.

PROGRAM PURPOSES:

The purposes of Program Options are: 1) to make available for developmentally disabled persons resources that are appropriate to their needs, 2) to allow these persons to live in the least restrictive, most independent way possible, and 3) to demonstrate that positive measurable outcomes can be achieved and costs can be saved when individualized community programs are developed.

The purpose of the Community Alternatives Program is to expand the existing service capacity in order to provide adequate community options for residents of ICF/MRs and to prevent institutionalization of the "at risk" population.

PROGRAM TYPE:

Supportive Services and Funding

ELIGIBILITY CRITERIA:

Persons who are eligibile for services from the Division of Developmental Disabilities and who are currently receiving some kind of service funded by the Department of Social and Health Services are eligible for Program Options. There are no age or income eligibility restrictions.

To be eligible for CAP, a person must be disabled according to the criteria in the Social Security Act, have a gross income that does not exceed 300 percent of the SSI benefit, need an ICF/MR level of care, have a qualified plan of care, have access to needed services, and express a desire for waivered services.

EXPENSE AND SERVICE LIMITS:

As stated in the law authorizing the Program Options initiative,, the only limit imposed is that the cost of the alternative plan cannot cost more than 80 percent of the cost of current services. The law does allow for exceptions to this requirement.

Limits on the Community Alternatives Program are similar. The client service budget must show that waivered services can be provided at 80% of the cost of institutional (ICF/MR) services.

NUMBER SERVED:

As of May 1984, nine applications had been received by the Division of Developmental Disabilities. Of those, eight were approved and one was in the process of being reviewed.

Estimates of the number of persons receiving services under the Community Alternatives Program ranged from 80 to 90 families.

PERMISSIBLE SERVICES:

An alternative Program Options plan may include provisions for "care, treatment, hospitalization, support, training or rehabilitation provided by state programs or services for the handicapped," (Chapter 60, Substitute House Bill No. 187).

The state's waiver application lists the following services under the Community Alternatives Program: case management, habilitation, respite (in-home and off-site), nursing services, equipment and supplies, physical therapy, occupational therapy, speech therapy, audiology, behavior therapy, dental and medical care.

AMOUNT AND SOURCE OF APPROPRIATIONS:

Because the criterion of lower cost is a central feature of Program Options, no new appropriations were deemed to be needed. Essentially, monies used to support individuals in their current situation are applied to the alternative plan which, by definition, is less expensive than the original plan.

STRENGTHS:

Both the Program Options and CAP initiatives provide strong financial incentives to move developmentally disabled individuals out of institutions and to prevent individuals from going into institutions. Both programs also make it possible to utilize a variety of community services to support families that choose to maintain their family member at home.

Approximately 50% of the funds available for the CAP initiative come from the federal government through the Medicaid program. The remainder comes from the state's Medicaid match. The magnitude of the total program is approximately $2 million.

WEAKNESSES:

While these financial incentives hold enormous promise, some of those interviewed felt that the programs had not been sufficiently advertised and that few families were aware of the benefits. With respect to CAP, one parent noted that instead of providing support, those administering the CAP program constantly questioned her judgement about what was needed and required continuing justification for the level of her need for attendant care. This was in spite of the fact that out-of-home placement for her child would cost significantly more than the current attendant.

Finally, parents require a substantial amount of information and sophistication to participate both in the creation of an alternative plan, and in its implementation. This fact may make it difficult for disadvantaged families to participate.

APPENDIX FOUR:

VIRGINIA FAMILY NEEDS SURVEY QUESTIONNAIRE

COMMONWEALTH of VIRGINIA

JOSEPH J. BEVILACQUA, Ph.D.
COMMISSIONER

Department of
Mental Health and Mental Retardation

MAILING ADDRESS
P.O. BOX 1797
RICHMOND, VA 23214

Dear Parents and Family Members:

Please help us. We have received a federal grant to study ways in which the Commonwealth can help families meet the special needs of their members with disabilities. We are asking you to participate in this worthwhile project.

Together with the Human Services Research Institute (HSRI), we already have examined what other states are doing to help families. But before this project can proceed any further, families in Virginia must let us know what some of their major problems are with regard to caring for their members with disabilities. Toward that end, we would like you to answer some questions about your family and the special needs that you or your disabled family member may have.

Please know that your participation is voluntary and all information that you provide will be kept strictly confidential. Your name will not be used and resulting reports will use only numbers obtained from all the surveys combined. Your participation will have no effect on the services you receive now or wish to receive in the future.

If you have any questions, you may call Ms. Shirley Ricks (804/786-3710) in the Office of Mental Retardation and Developmental Disabilities.

Please help us learn of your needs by completing and returning the enclosed survey form. Thank you for your cooperation.

Sincerely,

Joseph J. Bevilacqua, Ph.D.
Commissioner

Valerie J. Bradley
Project Director
Human Services Research Institute

Enclosure

INSTRUCTIONS

Thank you for helping us. Your cooperation will make it possible to improve services for persons with developmental disabilities in the Commonwealth of Virginia.

If you fill out this questionnaire by yourself, you can expect that it will take approximately 20-25 minutes to complete. However, some people would rather fill out this kind of questionnaire with a spouse or a relative or a friend helping them. This is fine, but may result in it taking a little longer to fill out. Regardless of how many people participate, please come to an agreement and mark only one answer.

Instructions are included throughout the questionnaire. We ask that you particularly note whether the instructions ask for a single answer or for all those that apply. We ask that you not indicate more than one answer when the instructions say "CHECK ONE" or "CIRCLE ONE."

You should remember that your answers will be kept strictly confidential. Should you come to a question you feel uncomfortable about answering, skip it. However, for us to get complete information, it is very important that you try to answer each question as accurately as you can.

When you have completed the questionnaire, remember to return it to us in the enclosed pre-addressed and pre-stamped envelope. PLEASE TRY TO SEND US YOUR COMPLETED QUESTIONNAIRE WITHIN THE NEXT TWO WEEKS!

THANK YOU

Today's date is: ________________.

PLEASE TURN THE PAGE

Send Completed Questionnaire to:

Shirley Ricks
Office of Mental Retardation and
Developmental Disabilities
PO Box 1797
Richmond, VA 23214

SURVEY OF FAMILIES WHO HAVE A MEMBER WITH A DEVELOPMENTAL DISABILITY

No:________
Sample:____

PART I: FAMILY INFORMATION

1. What is your relationship to your family member with a disability? (CHECK ONLY ONE)

__ natural parent
__ adoptive parent
__ foster parent
__ step parent
__ other -specify:____________

2. What is your mailing address zip code? ____________________

3. Please list ALL FAMILY MEMBERS living in your house, their AGES, and whether or not they are EMPLOYED.

DO NOT COUNT YOUR FAMILY MEMBER WITH A DISABILITY IN THIS LIST BUT REMEMBER TO INCLUDE YOURSELF. Please only write down the family member's relationship to the disabled person (mother, father, aunt, brother, grandmother, etc.) NO NAMES PLEASE

RELATIONSHIP	AGE	EMPLOYMENT STATUS			
		Homemaker	Employed Full Time	Employed Part Time	Not Employed
1.______________					
2.______________					
3.______________					
4.______________					
5.______________					
6.______________					
7.______________					
8.					

4. Other than your family member with a disability (for whom you are completing this questionnaire), are their any other persons living in your household who have significant health or emotional problems? (CHECK ONE ONLY)

___ YES ___ NO

5. What was the TOTAL taxable income last year (1984) of primary wage earners in your household? (CHECK ONE ONLY)

__ $0 - $9,999
__ $10,000 - $19,999
__ $20,000 - $29,999
__ $30,000 - $39,999
__ $40,000 - $49,999
__ $50,000 or more

6. Does your FAMILY MEMBER with a disability receive any of the following government benefits? (CHECK ALL THAT APPLY)

__ NONE (none of the government benefits listed below are received)

__ Supplemental Security Income (SSI)
__ Social Security Disability Insurance (SSDI)
__ Medicaid
__ Medicare

7. Does your family household receive any of the following forms of financial assistance? (CHECK ALL THAT APPLY)

__ NONE (no forms of financial assistance are received)

__ Aid for Dependent Children (AFDC)
__ Food Stamps
__ General Relief
__ Pension/ Rail Road or Veterans Benefits
__ Private Disability Insurance
__ Unemployment Insurance
__ Child Support/Alimony
__ Auxiliary Grant
__ Social Security
__ Other______________
____
____

PART II: INFORMATION ON YOUR FAMILY MEMBER WITH A DISABILITY

8. How old is your family member with a disability? ___years ____months

9. What sex is your family member with a disability? __ Male __ Female

10. What disability best describes the condition your family member with a disability has? (CHECK ALL THAT APPLY)

__ Don't know

__ Autism
__ Developmental Delay
__ Cerebral Palsy
__ Emotional Disturbance
__ Epilepsy
__ Hearing Loss
__ Mental Retardation
__ Muscular Dystrophy
__ Spina Bifida
__ Vision Loss
__ Physical Disability other than those listed--specify: ________________
____
__ Other --specify: ________________
____

11. To what extent has your family member's disability affected his or her MENTAL or INTELLECTUAL DEVELOPMENT (i.e., the capacity to learn new things and apply past learned skills as needed)? (CHECK ONE)

__ Not at all
__ Mildly
__ Moderately
__ Severely

12. To what extent has your family member's disability affected his or her PHYSICAL development (i.e., ability to move around or do things without the physical assistance of others)? (CHECK ONE)

__ Not at all
__ Mildly
__ Moderately
__ Severely

13. To what extent does your disabled family member require SPECIALIZED MEDICAL ATTENTION (i.e., from doctors or nurses to monitor health status or provide specialized health care)? (CHECK ONE)

__ No Need
__ Some Need
__ Moderate Need
__ Extreme Need

14. How often does your disabled family member behave in ways that pose a considerable problem for you or other family members (e.g., has excessive tantrums, breaks things, hits others, hurts himself or herself, eats unhealthy things)? (CHECK ONE)

__ Never
__ Sometimes (occasionally)
__ Regularly
__ Very frequently

15. How much assistance does your disabled family member need to perform every day activities like eating, dressing, bathing, toileting, and toothbrushing?

__ Very Little
__ A Moderate Amount
__ Frequent
__ Almost Constant

PART III INFORMATION ON FAMILY NEEDS

Below is a list of needs some families have in caring for their family member with a disability. Please rate from 1-5 YOUR family's PRESENT level of need by CIRCLING THE APPROPRIATE NUMBER. The lower the number you circle, the less need your family has. The higher the number you circle, the greater your family's need.

For example, if your family presently has NO NEED of "information on where to get special services," circle the number 1. If your family has an EXTREME NEED for that type of information, circle the number 5. If your level of need is somewhere in between, circle the number that best describes your family's overall present level of need. (CIRCLE ONLY ONE NUMBER PER STATEMENT)

	NO NEED				EXTREME NEED
16. Information on the type of disability my disabled family member has	1	2	3	4	5
17. Information on how or where to get services	1	2	3	4	5
18. Information on how to best care for my disabled family member	1	2	3	4	5
19. Information on planning for the future financial welfare of my disabled family member.	1	2	3	4	5
20. Information on how to deal with behavior problems displayed by my disabled family member	1	2	3	4	5

	NO NEED				EXTREME NEED
21. People who can come to my house and help me care for my disabled family member on short notice. .	1	2	3	4	5
22. Qualified persons to care for my disabled family member overnight	1	2	3	4	5
23. Other families with a disabled child with whom I can talk to about raising my disabled. . . . . . family member	1	2	3	4	5
24. A place where my disabled family member can go during the day while I do something else. . . . like go to work, school or shop	1	2	3	4	5
25. Time to complete household chores or routines (shopping, house cleaning...)	1	2	3	4	5
26. More time just for myself	1	2	3	4	5
27. Specialized services for my disabled family member like speech or physical therapy	1	2	3	4	5
28. More opportunities for recreation for my disabled family member like bowling, ... swimming, dancing, or summer camp	1	2	3	4	5
29. Money to use to care for my disabled family member	1	2	3	4	5
30. Temporary relief from caring for my disabled family member.	1	2	3	4	5
31. A way to transport my disabled family member around town when needed	1	2	3	4	5
32. Special equipment for my disabled family member (like arm or leg braces, a wheelchair, . . . special shoes or toys)	1	2	3	4	5
33. Modifications to our house to make it easier for my disabled family member to get around. . . . (like grab bars, ramp, wider doorways)	1	2	3	4	5
34. Medical insurance that covers more of the cost of medical care for my disabled family member . . .	1	2	3	4	5
35. Doctors who understand how to care for my disabled family member.	1	2	3	4	5
36. Dentists who understand how to care for my disabled family member.	1	2	3	4	5

PART IV: SPECIAL COSTS

Many families have extraordinary expenses related to providing care to their family member with a developmental disability. These next few questions request information on some of the costs your family may have had.

37. IN THE PAST TWO YEARS, have you bought any special items or devices for your family member with a disability? (Examples include leg or arm braces, wheelchairs, special chairs, specially designed toys, respirator, monitoring devices, and other specially designed devices)

__ YES __ NO

If you checked YES, please estimate the TOTAL COST THAT YOU PAID for these items. (Remember only to count costs you had to pay in the past two years)

Total Cost: $ ________.

38. IN THE PAST TWO YEARS, have you paid for special modifications to your house to make it easier for your family member with a disability to get around or for you to provide care? (Examples include installation of grab bars in the bathroom, widening doorways, building a ramp or other special home alterations)

__ YES __ NO

If you checked YES, please estimate the TOTAL COST THAT YOU PAID for these alterations. (Remember only to count costs you had to pay in the past two years)

Total Cost: $ ________.

39. IN THE PAST TWO YEARS, have you paid for specialized medical or dental services for your family member with disabilities? (Examples include surgery, hospitalization or repeated office calls)

__ YES __ NO

If you checked YES, please estimate the TOTAL COST THAT YOU PAID for these services. (Remember only to count costs you had to pay in the past two years)

Total Cost: $ ________.

40. Please specify below any special devices or services related to the care of your family member with a disability that are needed but that you just cannot afford at this time.

Other Special Services or Devices	Approximate Cost
a.	
b.	
c.	
d.	
e.	

41. To meet the needs of your family member with a disability, has anyone in your household: (CHECK ONE OPTION PER QUESTION)

a. given up a paying job? __ YES __ NO

b. not taken a paying job? __ YES __ NO

c. refused a job transfer or promotion? __ YES __ NO

PART V SERVICES RECEIVED NOW

42. Please specify below which of the services listed are PRESENTLY received BY YOUR FAMILY to help you provide care to your family member with a disability. If you do not receive a specific service place a CHECK in the column marked "NO." If you do receive the service, place a check in the column marked "YES."

In addition, for those services received, please indicate whether your family pays a fee for all or part of these services. (CHECK ONE SERVICE PAYMENT CATEGORY FOR EACH SERVICE RECEIVED)

Service	Service Received?		Payment Category		
	NO	YES	Family Pays Total Cost	Family Pays Part of Cost	Family Does Not Pay
Day Care					
Homemaker (home health aide)					
Counseling					
Respite Care or Sitter Service					
Training in Parenting Skills					
Behavior Consultation					
Other:					

43. Please specify below which of the listed services are PRESENTLY received BY YOUR family member WITH A DISABILITY. If she or he does not receive a specific service place a CHECK in the column marked "NO." If s/he does receive the service, place a check in the column marked "YES."

In addition, for those services received, please indicate whether your family pays a fee for all or part of these services. (CHECK ONE SERVICE PAYMENT CATEGORY FOR EACH SERVICE RECEIVED)

Service	Service Received?		Payment Category		
	NO	YES	Family Pays Total Cost	Family Pays Part of Cost	Family Does Not Pay
Early Intervention/Preschool					
Special Education					
Regular School					
Sheltered Work Program					
Physical Therapy					
Speech or Hearing Therapy					
Counseling					
Recreation Program					
Mobility Training					
Other:					

44. Please specify which advocacy or self help organizations any members of your family belong to: (CHECK ALL THAT APPLY)

__ NONE

__ Association for Retarded Citizens (ARC)
__ United Cerebral Palsy (UCPA)
__ Society for Autistic Children
__ Epilepsy Foundation of America
__ Parent to Parent network group
__ Other -Specify: ________________
____
____

PART VI PLACEMENT PLANS

45. Are you planning to request that your disabled family member be placed in a living arrangement outside your home in the near future (0-3 years)? (For example, to a foster or group home, state residential facility or institution) (CHECK ONLY ONE)

__ YES, our family has already applied for an out-of-home placement and we are waiting to hear about our status

__ YES, our family is planning to request an out-of-home placement

__ DON'T KNOW YET --our family is discussing this issue but we have not decided on what to do

__ NO, our family has no plans to seek an out-of-home placement

If you checked YES or DON'T KNOW YET, please specify why you have requested or may request an out-of-home placement. (CHECK ALL THAT APPLY)

__ disabled person wants to live somewhere else (eg., group home, own apartment)
__ disabled person could live away from home on his or her own
__ disabled person is old enough to live with others his/her own age
__ disabled person needs more care than the family can provide
__ disabled person has severe medical problems that cannot be met at home
__ disabled person has behavior problems that cannot be controlled
__ disabled person has special needs that the family is unable to afford
__ need to devote more time to other family members
__ disruption of family life
__ family has legal problems
__ death or illness of primary family caretaker
__ doctor or other professional(s) have advised placement
__ can't get needed services in the home
__ Other -Specify: ________________________________
____
____

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE.
PLEASE CHECK TO SEE THAT YOU HAVE ANSWERED ALL THE QUESTIONS.
DON'T FORGET TO MAIL IT BACK TO US !! THANK YOU!

APPENDIX FIVE:

LIST OF PERSONS ATTENDING THE FAMILY CARE CONFERENCE

Ellen Covert
Rt 2, Box 109
Brook Neal, VA 24588

Cathy A. Davis
Mental Health Assoc.
PO Box 1106
Danville, VA 24543
804-792-3700

Dennis Deacon
Route 4
PO BOX 479
Madison Heights, VA 24572
804-847-4926

Lonnie Deaton
Southwestern State Hospital
502 East Main Street
Marion, VA 24354
703-783-6921

Carol Dennis
Central Va. Training Center
PO Box 1098
Lynchburg, VA 24505
804-528-6088

Evelyn Doyle
Route 2
PO Box 186
Crozet, VA 22932

Ronald Dozier
Central Virginia CSB
PO Box 2146
Lynchburg, VA 24501
804-384-9523

Jean Drapper
Southwestern Va. Training Center
Route 1, Box 415
Hillsville, VA 24343
703-728-3121

Kathy Drinkard
New River Valley CSB
210 Third Ave.
Radford, VA 24141
804-639-9369

Norma L. Everett
Central Va. Training Center
PO Box 1098
Lynchburg, VA 24505
804-528-6143

Mike Fehl
Dept. of MH and MR
PO Box 1797
Ricmond, VA 23214
804-786-3710

David Fitch
Dept. of MH and MR
PO Box 1797
Richmond, VA 23214
804-786-2991

Jennifer G. Fidura
Central Virginia Training Center
PO Box 1098
Lynchburg, VA 24505
804-528-6326

Constance N. Fletcher, Ph.D.
Southern Va. Mental Health Institute
382 Taylor Drive
Danville, VA 24541
804-799-6220

Barbara Fretwell
President
Va. Assoc. of Retarded Citizens
929 Dogwood Suckle
Waynesboro, VA 22980
703-942-3727

Susan Gau
Rappahannock Rapiban CSC
401 S. Main Street
Culpepper, VA 22701
703-825-4344

PERSONS ATTENDING THE FAMILY SUPPORT CONFERENCE

AUGUST 6-7, 1985
LYNCHBURG, VIRGINIA

John M. Agosta, Ph.D.
Human Services Research Institute
120 Milk Street
Boston, MA 02109
617-542-1812

Benjamin H. Allen, Ph.D.
Southwestern Va. Training Center
Route 1, Box 415
Hillsville, VA 24343
703-728-3121

Donna G. Alvey
401 Macoy Avenue
Culpepper, VA 22701
703-825-5742

Ron Anderson
Southeastern Va. Training Center
2100 Steppingstone Square
Chesapeake, VA 23320
804-467-8281

Susan Baldridge
PLAN
PO Box 344
Charlottesville, VA 22902
804-295-0653

Thomas E. Bass Jr.
Dept. of Rehabilitative Services
4901 Fitzhugh Ave.
Richmond, VA 23230
804-257-0291

Samuel E. Beale
SETC and PAIR
2621 Brook Stone Drive
Cheseapeake, VA 23321
804-488-7201

Bobbie J. Beale
SETC and PAIR
2621 Brook Stone Drive
Cheseapeake, VA 23321
804-488-7201

Joseph J. Bevilacqua, Ph.D.
Commissioner
Dept. of MH & MR
PO Box 1797
Richmond, VA 23214
804-786-5682

Valerie J. Bradley
Human Services Research Institute
120 Milk Street
Boston, MA 02109
617-542-1812

Betty J. Burke
MH Services of the Roanoke Valley
920 S. Jefferson St. (Suite 410)
Roanoke, VA 24016
703-345-9841

Pat Burn
Southeastern Va. Training Center
2100 Steppingstone Square
Chesapeake, VA 23320
804-467-8281

Arthur W. Byrd Jr.
Dept. of MH & MR
PO Box 1797
Richmond, VA 23214
804-786-6148

Irene Carney
Parent Involvement Project
University of Virginia
164 Rugby Road
Charlottesville, VA 22903
804-924-3705

Mary Ellen Chewning
124 South Hampton Drive
Harrisonburg, VA 22801
703-434-3913

Lonnie Beth Coffey
MR Services of the Valley
413 Port Republic Road
Waynesboro, VA 22980
703-943-6604

Joyce S. Gilding
ARC Peninsula
PO Box 7394
Hampton, VA 23666
804-826-6461

Arlin O. Goad
Southwestern Va. Training Center
Route 1, Box 415
Hillsville, VA 24343
703-728-3121

Bert Goff
505 College Park Drive
Lynchburg, VA 24502
804-239-7826

Pamela J. Hart
Central Va. Training Center
PO Box 1098
Lynchburg, VA 24505
804-528-6150

Joanne Harvey
Route 1
PO Box 446
Crimora, VA 24431
703-943-1618

Elitta Heath
Va. State Health Department
5001 West Broad Street
Richmond, VA 23230
804-281-9536

Marie Hemphill
Central Virginia CSB
405 Bay Street
PO Box 2513
Lynchburg, VA 24501
804-846-4621

Linda Hindle
ARC Greater Prince William
4391 Davis Ford Road (Suite E)
Woodbridge, VA 22192
804-690-4240

Terry Hoban
Dept. of MH & MR
PO Box 1797
Richmond, VA 23214
804-786-4982

Esther Holden
Dept. of MH and MR
Catawba Hospital
Catawaba, VA 24071
703-387-1157

April Holmes
Region Ten CSB
413 East Market Street (Suite 103)
Charlottesville, VA 22901-5213
804-972-1800

James E. Hulse
Central Va. Training Center
PO Box 1098
Lynchburg, VA 24505
804-528-6473

Curtis Iddings
Woodrow Wilson Rehab Center
Dept. of Rehabilitation Services
Fishersville, VA 22939
703-885-9619

Janice Jordan
Dept. of MH & MR
PO Box 1797
Richmond, VA 23214
804-786-4982

Walt Kimpel
Dept. of MH & MR
PO Box 1797
Richmond, VA 23214
804-786-3060

Kenneth Kuester
Woodrow Wilson Rehab. Center
Dept. of Rehabilitation Services
Fishersville, VA 22939
703-885-9619

Andrea M. Lazzari, Ed.D.
Early Childhood Programs for
the Handicapped
Va. Department of Education
101 N. 14th Street
Richmond, VA 23219
804-225-2873

Gale Lavesque, Ph.D.
Eastern State Hospital
Drawer A
Williamsburg, VA 23287-3701
804-253-5486

Ann L. Lecheler
600 Biltmore Avenue
Lynchburg, VA 24502
804-845-0876

Jana Ledford
Central Va. Training Center
PO Box 1098
Lynchburg, VA 24505
804-528-6992

H.K. Lee
Dept. of MH & MR
PO Box 1797
Richmond, VA 23214
804-786-3710

Sandra MaGee
Systems Advocacy Director
Dept. of Rights for the Disabled
101 North 14th Street (17th Floor)
Richmond, VA 23219
804-225-2042

Diane L. Martin
Danville-Pitts Mental Health Clinic
326 Taylor Drive
Danville, VA 24541
804-793-4922

Deborah Mason
Mt. Rogers Community Services Board
770 West Ridge Road
Wytheville, VA 24382
703-228-2158

Bea Matheson
3544 Willow Lawn Dr.
Lynchburg, VA 24503
804-384-9366

Rema McCue
Highlands CSB
3279 Lee Highway
Bristol, VA 24201
804-669-3179

John McHugh
6633 Sylvan Brook Road
Roanoke, VA 24018
804-989-5839

Karleen McLeod
Eastern State Hospital
Drawer A
Williamsburg, VA 23287-3701
804-253-5486

Donna Meeker
4912 Blackfoot Crescent
Virginia Beach, VA 23462
804-497-9678

Robert Merryman
Central Va. Training Center
PO Box 1098
Lynchburg, VA 24505
804-528-6220

Esther B. Mills, Ed.D.
4409 Goodview Street
Lynchburg, VA 24502
804-237-1458

Marie Moore
Dept. of MH & MR
PO Box 1797
Richmond, VA 23214
804-786-3908

Jerry O'Bryan
4912 Blackfoot Crescent
Virginia Beach, VA 23462
804-497-9678

Fred Orelove, Ph.D.
Division of Educ. Services
Virginia Commonwealth Univ.
1015 West Main Street
Richmond, VA 23284
804-257-1305

April Passwaters
ARC Peninsula
51 Battle Road
Hampton, VA 23666
804-826-6461

Anne T. Peet
Eastern State Hospital
Drawer A
Williamsburg, VA 23287-3701
804-253-5486

John Pezzoli
Region Ten CSB
413 East Market (Suite 103)
Charlottesville, VA 27901
804-972-1800

Sakineh M. Redjali, Ph.D.
Central Va. Training Center
PO Box 1098
Lynchburg, VA 24505
804-528-6088

James Reese
Eastern State Hospital
Hancock Geriatric Treatment Center
Drawer A
Williamsburg, VA 23187-3701
804-253-5244

Chuck Richey
MR Services of the Valley
413 Port Republic Road
Waynesboro, VA 22980
703-943-6604

Shirley Ricks
Dept. of MH & MR
PO Box 1797
Richmond, VA 23214
804-786-3710

Dr. Richard Rowland
546 Elmwood
Lynchburg, VA 24503
804-845-2061

Mark Russel
Central Va. Training Center
PO Box 1098
Lynchburg, VA 24505
804-528-6220

Michael Sachs, Ph.D.
Univ. of Maryland
Walter P. Carter Center
630 West Fayette Street
Baltimore, MD 21201
301-528-2140

Dolores Sanders
1335 Fenwick Drive
Lynchburg, VA 24502

Cathy Saunders
Dept. for the Aging
101 North 14th Street (18th Floor)
Richmond, VA 23219
804-225-2271

George Schultz
1362 Westmoreland Ave.
Norfolk, VA 23508
804-423-6445

Mary Schultz
1362 Westmoreland Ave.
Norfolk, VA 23508
804-423-6445

Carol Singer-Metz
Dept. MH and MR
PO Box 1797
Richmond, VA 23214
804-786-ZZZZ

Michael Smull
Univ. of Maryland
Walter P. Carter Center
630 West Fayette Street
Baltimore, MD 21201
301-528-2140

Sally Spill
Dept. of MH and MR
PO Box 1797
Richmond, VA 23214
804-780-8296

Kathryn St. Clair
Alexandria CSB
206 N. Washington St. (Suite #1)
Alexandria, VA 22314
703-838-5060

E.T. Swink
910 Preston Ave.
Blacksburg, VA 24060
703-552-5447

Barbara J. Townsend
Eastern State Hospital
Drawer A
Williamsburg, VA 23287-3701
804-253-5486

Shirley Traversy
Dept. of MH and MR
PO Box 1797
Richmond, VA 23214
804-786-5313

Stephanie Van Gulden
Rappahannock Rapiban CSC
401 South Main Street
Culpepper, VA 22701
703-825-4344

Helen Villadon
Red Cross Assoc.
1105 Rosehill Dr.
Charlottesville, VA 22901
804-979-0328

Brenda Walker
Infant Development Coordinator
Southside Community Services
PO Box 488
South Boston, VA 24592
804-572-6916

Dawn Wilson
Central Virginia CSB
405 Bay Street
PO Box 2513
Lynchburg, VA 24501
804-846-4621

Wriley Wood
14 Canterbury
Charlottesville, VA 22901
804-293-9623

Daily Wright
1540 Link Road
Bedford, VA 24523
804-586-2906

Elsbeth Wyatt
Administration on Developmental
   Disabilities
Dept. of Health and Human Services
200 Independence Ave. (Room 348 F1)
Washington, DC 20201
202-245-2904

APPENDIX SIX:

TEXT OF THE KEYNOTE ADDRESS DELIVERED AT THE FAMILY CARE CONFERENCE

BY

IRENE CARNEY

KEY NOTE ADDRESS
FAMILY CARE CONFERENCE

Irene Carney

I'd like to begin my comments this evening by asking you to do something for which many a nervous dinner speaker might secretely have wished. I'd like for you to leave this dining room. Because I'm certain that many a dinner audience has wished for such an invitation,let me hasten to clarify that I intend for us to leave, for now, only on our imaginations.

This morning, we heard the collective voices of hundreds of Virginia families who, through the survey described this morning, inform us of the general state of affairs experienced, in our Commonwealth, by families that include a person with a disability. Today, we have begun to generate ideas and concerns about the "big picture" of what a statewide service plan should resemble. I'd like for us to adjust our focus now, and to hear from among those voices, and to see in the midst of that picture, the stories of a few of the families with whom we are concerned.

So let us, momentarily, imagine ourselves, not in the Lynchburg Radisson, but in the dining room of a modest but comfortable home in central Virginia. We would share our dinner here, not with colleagues, but with a couple in their late twenties. This husband and wife are probably, on this Tuesday evening, somewhat weary having both arrived home from full-time jobs. And now they are providing dinner for, and shifting their attentions to, their two young children. Their older child, a son, is being slowly and methodically fed. He has cerebral palsy - severe spastic quadreplegia - and is labelled mentally retarded as well. Their long and patient dinner routine is but one of many demands this couple faces. They must accommodate, too, the many demands this couple faces. They must accommodate, too, the implications of a dual career, marriage, parenthood, and the other numerous, special needs of their younger son. They also fortunately, have ample resources. They have a strong marriage, a comfortable income, and, through the wife's sister who lives with them, abundant help with child care and the management of household tasks. The mother, furthermore, belongs to a parent support group of which she is a founding member. She reports the importance of this experience in gathering information and garnering support. But this couple's home is in one of the more rural areas of our state. Their local school system has yet to provide the full range of services that their son very much needs. He attends school for only a portion of the day. He has access to limited physical therapy services, but for more physical therapy and for occupational therapy, the parents have been told repeatedly that they will have to use an outpatient clinic 50 miles away. The mother, who represents her family to the schools, feels frustrated by the district's limited resources and even more upset by their apparent lack of concern. She is also concerned that the elementary school teacher to whom her son will graduate, has not been trained to work with children with severe and complex problems. She believes that with skillful instruction, her son could achieve some measure of independence. Her husband, we should note, does not believe that his son's life can be at all "normalized". He also disagrees with his wife on the topic of disciplining this child. This father's general response to his son is one of pity and indulgence. Husband and wife do agree, like so many families, that they can't foresee their son ever living in a residence other than their own.

In that same district, but on the other side of the county, resides a family whose home is, by most standards, luxurious. The mother, who would greet us this evening, is 20 years older than the mother we visited first. But she seems more rested and energetic. She does not work outside of her home and her three children are older. Only one of them continues to require much care - her 21 year old son, categorized profoundly mentally retarded. This couple, unlike the first, were very satisfied with their district's Special Education program. But their son has just graduated and his next step is unclear. There is an adult day program for which he is eligible, but their remote location makes transportation problematic. These parents _are_ interested in group home placement, but their son is not sufficiently independent to qualify for the one group home in their area. So it's likely that he'll be at home -- with a teenage sister who is, these days very embarrassed by, and resentful of, her brother's differences. This husband and wife are generally optimistic, but their values dictate that their son be involved with some meaningful activity. And they want, like every parent, for their child to have friends and, through friendship, emotional satisfaction. It is hard for them to imagine who will care for him, or about him, when they are gone.

For our final step on this tour, let us go quickly to the apartment of a single mother who lives in a small Virginia city in the Western part of the state. Her two teenage children are both recipients of Special Education -- her son for behavioral and emotional difficulties, her daughter because of moderate mental retardation. This woman is in her late thirites. She would like to work, but has found it hard to coordinate a work schedule with her responsibilities as a parent, so she relies on Public Assistance. This mother, like the second family, has been pleased with the school's services. Her daughter's high school program is preparing for her transition to work, and she receives all needed related services at school. But the hours that her children are not in school weigh heavily on this woman. Her ex-husband lives nearby, but she feels the burden of full responsibility for her children. She feels isolated. She knows that the option for respite care exists, but feels that she can't afford it. She would like, very much, to know that other people understand and support her. She would like very much to feel better able to attend to her own personal needs.

Having made these three imaginary house calls, I invite you back, now, to the Lynchburg Radisson and to this business of this Family Care Conference. The families that, in our minds' eyes, we've just visited, represent a range of resources and a comparable range of needs. They and the parents that we've heard from here today, demonstrate the influence of a variety of factors including the nature of the handicap; the number of people involved in caregiving; the ages of the parents and their children; the family's financial stability; and the range and adequacy of local services. Among them, we've seen the need for comprehensive educational services, implemented by skilled professionals. They illustrate the need for expanded options for employment, vocational training, or other meaningful adult activity. We've seen the need for a variety of respite care provisions. We've heard from families whose children currently live at home, but who would like for their child to some day have other options. These families wish for residential alternatives that are close enough for families to maintain their relationships with one another, and that are stable and responsibly managed. Among the families I've described, we've seen the need for affordable programs of financial assistance that will equalize access to services. Financial needs also include financial guidance featuring long term estate and guardianship plans.

Some families dominant need is for information. And in a more personal, emotional vain, parents report that they benefit from support, from within their families or from parent support and advocacy groups; and from assistance, when requested, with communication, problem solving, and conflict resolution in the face of difficult decisions.

This list is a familiar one. All of these services,and more have been mentioned, or will be, I suspect, during the course of our presentations and discussions. Many of these features are already evident, albeit inconsistently, in our state. And as we generate and examine these lists, we fantasize, individually and collectively, about the day when each family in Virginia can choose and have ready access to any needed service from this array. But this conference is not about pipe dreams. We need to ask ourselves "What are our prospects for realizing this fantasy?". And "How do we proceed?" As a tentative response to those questions, I offer a proposal and a perspective. The proposal is inspired by a cartoon that's posted, in my office, where I can see it from my desk. The drawing features three people sitting at a bar. One gentleman is very neatly and fashionably dressed. His tie is tightly knotted. He's sitting up in a dignified posture and drinking some exotic cocktail. Across from this customer sits a couple. The man, looking somewhat "down and out" is drinking a shot and a beer. His cohort, a woman wearing a frumpy hat and clutching her handbag in front of her, gestures to her partner and says "My Raymond here thought up the Banana Daiquiri, but he never did anything about it."

My proposal is that we guard against the risk of one day resembling Raymond ... that we aim to avoid the ultimate confession that we came up with varied and innovative ideas for Family Support in Virginia, but never did anything about them. We may never fully realize the visions we generate over these two days. But we can, at least, use the ideas and energy generated by our work together to undertake the long and patient travel to that end.

For the perspective, I'd like for us to think back, for a moment, to our three families and one way in which these very different families are alike. Each of the parents we've considered regards their child with a deep parental love. From that love, stem a variety of concerns, perhaps foremost among them, the fervent wish that their child will know acceptance, respect, affection, and happiness. To this end, family members are vigilant in their dealings with those of us who teach, supervise, employ, or live with their children. And, in this respect, perhaps there is no way in which we can be more responsive to families' needs than to evidence skill and energy and committment in our efforts. I know from my experiences as a member of such a family that we've faced no transition or crisis that wasn't eased by professionals who treated us with honesty and empathy. Conversely, we had no interaction, however, trivial, that wasn't sadly transformed by our perception that our loved one was just another bothersome statistic on someone's already heavy caseload.

So as we continue the process of shaping local and statewide programs of family care, and particuarly as we face the inevitable conclusion that we're never doing enough, let us remember this:

> By, as family members, extending ourselves to one another
>
> By, as professionals, working to the limits of our skill
>
> By treating our students and clients with respect
>
> By demonstrating to families that our work with them is not a necessary evil but a priority concern

By these means, we can advance the status of Family Support in Virginia by taking and retaking each day, the first and most fundamental steps.